Views and experiences of informal caregivers of older adults with dementia in Sri Lanka: a phenomenological study

by

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Academic Honesty Declaration

I, Mudun Pitage Kalpani Wasantha Abhayasinghe do hereby declare that,

- The work reported in this thesis was initiated, designed and exclusively carried out by me under the supervision of Dr Benjamin Saunders, Dr Paul Campbell and Professor Athula Sumathipala.
- The thesis being submitted for examination is my own account of my own research. The material presented is not submitted in whole or part in any other degree qualification. The research has been conducted ethically.
- Letters from the Ethical Review Committees from both the UK and Sri Lanka confirming that ethical approval has been given has been bound into the thesis as appendices.
- The data and results presented are the genuine data and results actually obtained by me during the conduct of the research.
- Where I have drawn on the work, ideas and results of others this has been appropriately acknowledged in the thesis.
- The work described in the thesis has been undertaken subsequent to my registration for the PhD for which I am submitting for examination.
- The thesis submitted is within the required word limit as specified in the regulations.

Kalpani Abhayasinghe Date: 15.03.2020

Abstract

Introduction:

Dementia is a global health concern affecting an estimated 115.4 million people. Dementia has become a research priority in low-and-middle income countries (LAMIC), due to increasing prevalence associated with demographic transition and ageing population. Research on informal dementia caregivers; their cultural and traditional views and experience in LAMIC is scares.

Aim:

This study explores views and experiences of informal caregivers for older adults with dementia in Sri Lanka.

Methods:

The study was underpinned by a phenomenological approach. Twenty-six in-depth semi-structured interviews were conducted with a purposive sample of informal dementia caregivers living in a semi-urban area in Colombo, Sri Lanka. Data analysis was carried out using Interpretative Phenomenological Analysis.

Results:

Overarching findings consist of three super-ordinate themes: meaning of dementia; meaning, practice and purpose of caregiving; and caregivers' concerns, issues and challenges. Caregivers attributed diverse meanings to symptoms and causes of dementia and caregiving. A shift in their initial views of illness perceptions and causations of dementia symptoms was noted along the journey of caregiving. Dementia awareness was low among majority of caregivers. Alternative traditional healing methods were widely

practised, as first-line and sole treatment for dementia or as a complementary treatment along with western medical treatments. Experience of burden was often driven by either caregiving activities with people with dementia (PwD) or the wider socio-cultural context. Caregivers were concerned about the service gaps in health care system.

Conclusions and Recommendations:

Caregivers' personal values, beliefs, attitudes and their socio-cultural and religious views largely influenced the conceptualisation of meanings of dementia and caregiving role. The findings highlight the importance of increasing dementia awareness in the study context and developing facilities and health care services to support PwD and their family caregivers. Integration of western medical care model and traditional or complementary care models will be beneficial in this particular socio-cultural context.

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Dedication

To all the older adults who live with dementia and the wonderful family caregivers who help them to walk the journey.

To my late father, my hero.

Preface: personal narrative

My strong interest in the development of this research idea was influenced by my own experience, having a relative and a close family friend with dementia; and also, my experience as a nurse.

I first became aware of dementia when one of my uncles developed noticeable changes in his behaviour when I was just a teenager. Our family had no idea of the reason for his behavioural change and the continued deterioration of his usual functioning until my mother, who was also a nurse, explained to us about dementia. I was so worried to see how my aunt, who was in her early seventies at that time, struggled in supporting my uncle's activities of daily living, especially when my uncle started wandering the roads. His memory and his ability to perform daily activities deteriorated over time and my aunt was going through a hard time. He had many complaints for no reason and became really aggressive over trivial reasons. Since they had no children it was my aunt who had to manage everything. The caring role affected many aspects of her life, including her health, income, social interactions and overall quality of her life. I noticed many times 'how depressed' she was during the late stage of the disease. She was living with immense fear of losing her husband and also feeling guilty that she would not be able to take care of him. My mother, being a nurse, took some responsibility in caring for him, allowing my aunt to relax for a while. But my aunt was reluctant to accept help and frequently refused our support thinking that it would become a burden for us.

I found most of the visits to them very distressing and the experience I had was pretty awful. The neighbours thought my uncle was *'crazy'* and often appeared to be scared

of him and therefore avoided him. The neighbourhood children even laughed at me and my brother during our playtimes, and said hurtful things about my uncle's behaviour. This actually became a source of significant psychological trauma to my aunt; she ended up avoiding neighbours and isolating herself. It was difficult for her to face the stigma; she was even reluctant to meet the doctor. My uncle suffered for nearly eight years before he died from Alzheimer's disease. Today as an adult I understand that if we had had more insight and been more open about his illness, we could have made his journey more comfortable and our lives too.

A few years later, my best friend's grandmother developed dementia. According to my friend, her grandma's wish was to remain at home until she died. The family members were able to honour that wish for several years by having a paid caregiver to look after her for a few hours a day, especially when others were out at work. However, since 2015 her physical and cognitive decline have accelerated. She began to drop things on the floor, she forgot her last meal she had had a few minutes before, and forgot how to find the toilet and passed urine wherever she was. She was falling an average of three times a week but refused to go to the hospital to be examined for injury. On the advice of her physician, and as a result of the difficulty of taking care of her at home due to increasing physical disability, cognitive lapses, and needing constant care, the family finally decided to move her into assisted living. However, my friend still thinks that she has committed the worst sin – moving her grandma into a place against her will, where she gets the care she needs, but not the care she wants.

However, it was at the geriatric ward at the National Institute of Mental Health - Sri Lanka (NIMH) where I first became interested in nursing older people with dementia during my clinical placement as an undergraduate nursing student. Once I became an

academic, I started teaching mental health nursing for nursing undergraduates and visited the same ward with my students several times. There were two geriatric wards at NIMH caring for nearly a hundred people with dementia and other mental illnesses. I witnessed myself how the older adults were treated in the hospital. The wards were dark, crowded and smelly. The nurses were struggling with staff shortages, alongside a lack of specialised skills to care for patients with dementia and there was no person-centred approach to care for each individual patient. There was minimal or no communication between the patients and the staff. Most patients were almost abandoned by their families. During this time, I started educating myself about dementia care and how to encourage home-based provision of care for people with dementia; meanwhile, I got the opportunity to pursue my PhD relating to this topic.

After coming to Keele University I had an opportunity to work in the older adults' care unit in the university hospital and later in a nursing home for older people with dementia. I worked in these units with an inspiring, dedicated care team and residents who were at various stages of dementia. It was an eye-opening experience for me to be exposed to the dementia care models and services available to patients and their family members within the UK health care system. It was fascinating to see the friendly environment where everyone was so committed to caring for these residents and their families. I was constantly comparing these dementia-friendly care settings with the current situation in Sri Lanka. I also learned how care is provided in the community in the UK during my home and community visits with one of the nurses. This was indeed a golden opportunity for me to get a real-life experience of formal and informal dementia care in the developed world.

However, what I have learned from my personal and work life is how difficult it is for any family member to care for someone with dementia, to become the agent for decision making on behalf of him/ her and to inhibit his/ her independence even if it is in the best interests of their health and safety. What I learned from my aunt's experience was that living with a person with dementia, and providing long term care until to the end-of-life, is fraught with peril for caregivers, and the accompanying feelings of guilt and frustration may never end even after many years following the death of the loved one. After more than eight years of care and about five years after he passed away, my aunt still cannot access her memories and the feeling of guilt and frustration about not being able to treat her husband without being hostile. *"He couldn't even recognise who I am"* is her major worry and she still thinks it is all her fault.

I used to communicate with the White family members when they visited the nursing home to see their loved ones. This enabled me to understand family caregivers' views and concerns from a UK perspective. I saw the socio-cultural differences in Sri Lanka and the UK especially when it comes to their perspectives and understanding of dementia, its symptoms and especially attitudes seeking help, openness towards issues of caregiving and placing loved ones in a care home. Dementia is still less commonly diagnosed in Sri Lanka perhaps because lack of awareness and stigma associated with mental illnesses are common. In Sri Lanka, providing care for older adults is largely influenced by the socio-cultural norms and family members face many challenges when continuing care. There may be issues and difficulties when providing care for people with dementia at home with inadequate knowledge and support. In the UK, for instance, some people may react with fear in the very early stages, but it may

be more likely that people would recognise that someone could have dementia and be motivated to seek medical advice and required care promptly. I have observed a huge difference in the services for people with dementia and their families between Sri Lanka and the UK, especially at the community level. These experiences opened my eyes to the commonalities and differences between dementia care in Sri Lanka and UK highlighting the importance of my PhD in the Sri Lankan context.

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List of Abbreviations

AD – Alzheimer's Disease

ADI – Alzheimer's Disease International

ADL – Activities of Daily Living

BPSD – Behavioural and Psychological Symptoms of Dementia

CAMCOG - Cambridge Cognitive Score

CAMDEX - Cambridge examination for mental disorders of the elderly

CI – Confident Interval

DALYs - Disability-Adjusted Life Years

DHS – Demographics and Health Survey

DRG – Dementia Research Group

DSD – Divisional Secretariat Division

DSM – Diagnostic and Statistical Manual of Mental Disorders

FTD – Fronto-temporal Dementia

GDS – Global Deterioration Scale

GNI - Gross National Income

HCP – Health Care Professionals

HIC – High Income Country/ Countries

HIV – Human Immunodeficiency Virus

ICD – International Classification of Diseases

IPA – Interpretative Phenomenological Analysis

IPQ - Illness Perception Questionnaire

IRD – Institute for Research and Development – Sri Lanka

JBI - Joanna Briggs Institute

KDU – General Sir John Kotelawala Defence University

LAF - Lanka Alzheimer's Foundation

LAMIC – Low and Middle Income Country/ Countries

LMIC – Lower-middle Income Country/ Countries

MC – Main Caregiver

MCI - Mild Cognitive Impairment

MMSE – Mini-Mental State Examination

MoCA - Montreal Cognitive Assessment

MoH – Ministry of Health

MOH – Medical Officer of Health

NHSL – National Hospital, Sri Lanka

NIMH – National Institute of Mental Health

NPI - Neuropsychiatric Inventory

PGR – Post Graduate Research

PHC – Primary Health Care

PhD – Doctor of Philosophy

PwD – Person with Dementia/ People with Dementia

QALYs - Quality-Adjusted Life Years

RBANS - Repeatable Battery for Assessment of Neuropsychological Status

SC – Secondary Caregiver

TA – Thematic Analysis

UMIC – Upper-middle Income Country/ Countries

VD – Vascular Dementia

WHO – World Health Organisation

ZBI – Zarit Burden Interview

Chapter 01

Introduction

This PhD thesis explores the views and experiences of informal caregivers of older adults with dementia, within the context of Sri Lanka, one of the upper-middle income countries (UMIC) in South Asia. The thesis constitutes an investigation of the beliefs, thoughts, perceptions, and assumptions of informal caregivers about dementia and the caregiving role with findings considered against the backdrop of the existing literature on the caregiver experience. This research employs a phenomenological approach to explore the core essence of caregivers' experience of informal caregiving for older adults with dementia. Participants in this study were a purposefully selected group of family caregivers for older adults with dementia recruited from a localised dementia health service within district of Colombo, the capital of Sri Lanka.

This chapter provides an overview of dementia, including typology, pathophysiology and healthcare management. The chapter will also outline the epidemiology of dementia, globally, regionally and within Sri Lanka and touch upon relevant cultural influences concerning the understanding and management of dementia. A description of the study context, which includes key population characteristics and an overview of the health care system in Sri Lanka sets the context for the remainder of this thesis. Lastly, the rationale, significance, and purpose of the study will be presented along with a summary of the thesis structure.

1.1 Dementia

1.1.1 What is Dementia?

Dementia is an umbrella term for several pathologies involved in causing a global impairment of cognition which is beyond normal ageing (Cowen, Harrison and Gelder, 2012; Dupuis, Epp and Smale, 2004; Fieo *et al.*, 2017). Dementia (as an encompassing term) is a chronic, progressive and debilitating condition caused by death of neurons in the brain (Wang *et al.*, 2014); that affects higher brain functions such as intellect, memory and personality, but without impairment of consciousness (Cowen, Harrison and Gelder, 2012).

1.1.2 International classifications of dementia

Both International Classification of Diseases (ICD-11) and Diagnostic and Statistical Manual of Mental Disorders (DSM-5), the two main international classification systems, classify dementia as a 'neurocognitive disorder' (WHO, 2019). ICD-11 describes dementia as an acquired brain syndrome characterised by a decline from a previous level of cognitive functioning with impairment in two or more cognitive domains (such as memory, executive functions, attention, language, social cognition and judgment, psychomotor speed, visuo-perceptual or visuo-spatial abilities) (WHO, 2019). According to the ICD-11 definition, dementia begins with focal cognitive or behavioural disturbances, with impairment of two or more cognitive domains which includes speech, language, judgment, reasoning, planning and other thinking abilities (WHO, 2019). The DSM-5 details six cognitive domains when classifying neurocognitive disorders: complex attention, executive function, learning and memory, language, perceptual-motor function, and social cognition. In dementia, there

is a significant decline in these six domains with clear evidence of interference with activities of daily living (ADL) of the affected individual (*APA*, 2016).

1.1.3 Clinical presentation and stages of dementia

Dementia is a syndrome which may be caused by a number of illnesses in which there is progressive cognitive impairment which includes decline in memory, reasoning, communication skills and the ability to carry out ADL (Department of Health, 2009). Behavioural and psychological symptoms of dementia (BPSD) are common and can include changes in sleeping patterns, communication, wandering, repetitive questioning, agitation, depression or psychosis, as well as inappropriate behaviours such as sexual disinhibition, all of which can lead to social dysfunctioning of the person with dementia (PwD) (Kales, Gitlin and Lyketsos, 2015). The symptoms may vary according to the types and subtypes of dementia. One or more of these symptoms affect people with dementia (PwD) and may appear over the course of the illness (Kales, Gitlin and Lyketsos, 2015).

The pace at which these symptoms change may vary from person to person; it also reflects the degree of damage to affected neurons in the brain (Barker and Board, 2012; Alzheimer's Association, 2018). In the early stages, individuals may display mild cognitive impairment, which may or may not affect normal day-to-day functions. However, over time this may lead to gradual decline of communication and functional capacity of the PwD. Many PwD eventually become bed ridden and totally dependent on care from others as the disease progresses (Vaingankar *et al.*, 2016; Alzheimer's Association, 2018). The global deterioration scale (Reisberg *et al.*, 1982) outlines the sequence of cognitive impairment over time in a series of seven stages ranging from normal to very severe cognitive decline (See Table 1.1).

Table 1.1 The Global Deterioration Scale (Source: Reisberg *et al.*, 1982)		
Level of cognitive decline	**Clinical phase**	**Clinical characteristics**
None	Normal	• No subjective complaints or evidence of memory deficit during clinical interview
Very mild	Forgetfulness	• Subjective complaints of memory deficit, such as forgetting where one has placed familiar objects or forgetting names of known people. • No objective evidence of memory deficit on clinical interview, in employment or social situations.
Mild	Early Confusional	• Earliest clear-cut deficits appear in manifestations in day to day activities. (e.g. lost when traveling to an unfamiliar location, decreased performance at work place and social settings, difficulty in finding words and/or names become evident to intimates, concentration deficit may be evident on clinical testing) • Objective evidence of memory deficit can be obtained only with an intensive interview. • Denial, mild to moderate anxiety frequently accompanies symptoms.
Moderate	Late Confusional	• On careful clinical interview clear-cut deficit manifest in areas such as decreased knowledge of current and recent events, some deficit in memory of one's personal history, concentration deficit elicited on serial subtractions, decreased ability to travel, handle finances, etc. • Frequently no deficit in orientation to time and place, recognition of familiar persons and faces and ability to travel to familiar locations. • Denial is dominant, flattening of affect and withdrawal from challenging situations and unable to perform complex tasks.

Table 1.1 Global Deterioration Scale (Source: Reisberg *et al.*, 1982) *Continued…*		
Level of cognitive decline	**Clinical phase**	**Clinical characteristics**
Moderately severe	Early Dementia	• Patient can no longer survive without some assistance. • Inability to recall a major relevant aspect of their current lives (e.g. address or telephone number of many years, the names of close members of their family, etc.). • Frequently some disorientation to time (date, day of the week, season, etc.) or to place. But may retain knowledge of many major facts regarding themselves and others such as their own names, the spouse's and children's names. • Require no assistance with toileting or eating, but may have difficulty choosing the proper clothing to wear.
Severe	Middle Dementia	• They will be largely unaware of all recent events and experiences in their lives. • They always recall their own name but occasionally forget the name of the Spouse. • Retain some knowledge of their surroundings; the year, the season, etc. • Will require some assistance with activities of daily living. May become incontinent, require travel assistance. • Diurnal rhythm frequently disturbed. • Personality and emotional changes occur (e.g. delusional behaviour such as accusing the caregiver of being an imposter; may talk to imaginary figures, obsessive symptoms, anxiety symptoms, agitation, and even previously non-existent violent behaviour may occur.
Very Severe	Late Dementia	• All verbal abilities are lost over the course of this stage. Early in this stage words and phrases are spoken but speech is very circumscribed. Later there is no serviceable speech at all. • Incontinent; requires assistance toileting and feeding. • Basic psychomotor skills such as the ability to walk are lost. • Generalised rigidity and developmental neurologic reflexes are frequently present.

1.1.4 Types of dementia, pathophysiology and aetiology

Different underlying pathological conditions result in dementia, of which Alzheimer's disease (AD), vascular dementia (VD), dementia with Lewy bodies (DLB), fronto-temporal dementia (FTD) and mixed dementia are considered the most common (Barker and Board, 2012). AD is the most common subtype, up to 70 percent of the dementias are attributed in whole or in part to AD (Fiest *et al.*, 2016). The second and third most common types are VD (20%) and DLB (15%) and less than 5% cases are of the FTD subtype. Both VD and FTD may have several subtypes. Following is a brief description of the types of dementia, the symptoms and causes for each type.

Alzheimer's disease

AD likely develops from multiple factors, such as genetics, lifestyle and environment. In AD there is a gradual death of brain tissue and loss of connection between the nerve cells in the brain due to formation of abnormal protein structures called 'plaques' and 'tangles' (Eliopoulos, 2014). Memory impairment is the typical initial presenting complaint (WHO, 2019); difficulty in recalling recent events and learning new information are the commonest symptoms of AD (Alzheimer's Association, 2018; Alzheimer's Society, 2019). As the condition progresses, people with AD will experience difficulty in carrying out their day-to-day activities due to memory loss. Problems related to the affected person's thinking, reasoning, perception, communication and orientation also become severe in the later stages of AD (Eliopoulos, 2014).

Vascular dementia

VD is caused by problems with the blood supply to the brain; for example, cerebro-vascular diseases such as stroke, ischemia or haemorrhage (Eliopoulos, 2014; WHO,

2019). There are several forms of VD according to the underlying cause and which part of the brain is damaged; for example, stroke related dementia, single-infarct and multi-infarct dementia and sub cortical dementia (Alzheimer's Association, 2018; Alzheimer's Society, 2019). The most common form of VD is due to the damage of grey matter. When the white matter is damaged, the condition is known as 'Binswanger's disease'. The most distinguishing feature of multi-infarct VD is a pattern of stepped progression (corresponding to infarcts), this differs from a more gradual progression associated with AD. Common initial symptoms of VD are problems with planning or organising, decision making, problem solving and sequencing functions within a task (for example, cooking), as opposed to the effect on core memory which is primarily associated with AD (Eliopoulos, 2014; Alzheimer's Association, 2018). People with VD demonstrate confusion at the early stages and display more emotional and rapid mood changes, anxiety or depression (Kales, Gitlin and Lyketsos, 2015). Furthermore, they may also have difficulty with motor functions including slow gait and poor balance (Alzheimer's Association, 2018). However, the symptoms can vary according to the VD subtypes.

Dementia with Lewy bodies

DLB is associated with presence of Lewy body substance in the cerebral cortex; 25% of the people affected with DLB have a family history of dementia, suggesting a strong heritability component (Eliopoulos, 2014). However, the precise aetiology of DLB is unknown (WHO, 2019). People with DLB usually have symptoms of both AD and Parkinson's disease (PD). Impairment of consciousness is prominent in DLB; people with DLB may experience difficulties with attention and alertness (McKeith *et al.*, 2005; Alzheimer's Association, 2018). Similar to AD, day-to-day memory is often

affected in DLB, hallucinations and delusions are also more common in DLB compared to other dementias (Kales, Gitlin and Lyketsos, 2015).

Fronto-temporal dementia

FTD, also called Pick's disease, is caused by damage to the frontal and temporal lobes of the brain. There are three main subtypes of FTD: Behavioural variant FTD (the most common type), progressive non-fluent aphasia and semantic dementia (Robinson, Tang and Taylor, 2015; Alzheimer's Association, 2018). A unique characteristic of FTD is the behavioural changes seen in the early stages, as opposed to cognitive deterioration (Eliopoulos, 2014). In contrast to AD, at the early stages of FTD, affected people do not demonstrate problems with day-to-day memory or difficulties performing visuo-spatial skill related tasks (Robinson, Tang and Taylor, 2015). People with FTD may become less responsive, and less interested in their surroundings. Sometimes they may demonstrate socially inappropriate behaviours. People with FTD may also struggle with planning, organising things and decision making (Barker and Board, 2012; Eliopoulos, 2014).

Mixed Dementia

The symptoms of mixed dementia can present as a mixture of the symptoms of more than one type of dementia. It is estimated that the ten percent of PwD have more than one type at the same time (Robinson, Tang and Taylor, 2015; Alzheimer's Association, 2018). The most common combination is AD with VD, followed by AD with DLB and AD, DLB with VD (Robinson, Tang and Taylor, 2015; Alzheimer's Association, 2018).

Other types

In addition to the types of dementia outlined above, there are other types. To name some of them: Creutzfeld-Jacob disease , meningitis-neurosyphilis-AIDS- related dementia, and dementia caused by alcohol-related brain damage, heavy metal poisoning such as Lead, Mercury, or neurotoxins such as neuro-active organic compounds (Eliopoulos, 2014; WHO, 2019). These other types of dementia can present with common symptoms similar to AD; therefore, comprehensive evaluation is necessary to identify the causes and diagnose the condition (Eliopoulos, 2014; Alzheimer's Association, 2018). However, in most cases the true pathology can only be determined after death at autopsy (Eliopoulos, 2014).

1.1.5 Risk factors

Based on current evidence, there are many risk factors for dementia including both modifiable and non-modifiable factors. Age is the most important non-modifiable risk factor for dementia (Van Der Flier and Scheltens, 2005). However, it is possible to develop dementia at an earlier age; called early–onset dementia (Barker and Board, 2012). There is a genetic and environmental influence on some of the dementia subtypes (Kalaria *et al.*, 2008). Evidence suggests that females are at high risk of developing AD, while males are at higher risk of developing VD (Berr *et al.* 2005).

As outlined in the Lancet Commission on the 'Prevention and management of dementia: a priority for public health' dementia is a clinically silent disorder that begins at midlife; and therefore, identifies nine potential modifiable risk factors that could prevent more than one third of dementia cases, if eliminated. These risk factors include: low educational level in childhood, hearing loss, hypertension, obesity, smoking, depression, physical inactivity, social isolation, and diabetes (Frankish and

Horton, 2017). Cardiovascular diseases, hypercholesterolemia, hepatic and renal disorders are also major modifiable risk factors for dementia (Farid *et al.*, 2012; Eliopoulos, 2014; Deckers *et al.*, 2015). There is also a link between anxiety, depression and dementia (Kessing, 2012; Burton *et al.*, 2013; Deckers *et al.*, 2015; Gulpers *et al.*, 2016); both depression and dementia are associated with neurochemical changes; some forms of depression may be associated with damage to brain structure at subcortical level (Kitwood, 1997; Kessing, 2012). In some cases, childhood malnutrition, recurrent head trauma, excessive chronic use of alcohol and other substances may contribute to the development of dementia (Berr et al. 2005; Farid *et al.*, 2012; Wijeratne 2015).

Conversely, active engagement in mental, physical and social activities, higher education, and a healthy and balanced diet are the protective factors against dementia and can potentially delay the onset of dementia in later life (Basu, 2013; Beydoun *et al.*, 2014).

1.2 Management of dementia

The principal goals of management of dementia include early diagnosis with an aim to slow down the progression of disease, detection of BPSD and treatment in later stages, optimization of physical and psychological health, wellbeing of the PwD as well as of the caregivers, and the provision of support in long-term care (Prince *et al.*, 2009). This section will describe the screening and diagnosis of dementia, as well as the role of pharmacological and non-pharmacological interventions in the management of dementia. The caregiving aspects associated with dementia care will be discussed in detail in Chapter Two.

1.2.1 Screening and diagnosis of dementia

Screening and diagnosis are usually accomplished via cognitive testing, clinical interview, and physical examination, as well as through informant reports of cognitive and functional decline of the PwD if required. History, collateral history, clinical symptoms, cognitive tests and radiological investigation are conducted to rule out other significant causes of cognitive impairment. A large number of test instruments for dementia are available for screening, diagnosis as well as for research purposes. Common measures are; Mini-Mental State Examination (MMSE), Cambridge Cognition examination (CAMCOG) and Montreal Cognitive Assessment (MoCA) (Jacob *et al.*, 2007; Prince *et al.*, 2007; Umayal *et al.*, 2010; De Roeck *et al.*, 2019). Evidence encourages case finding among those at high risk of dementia; however, screening all older people is not recommended because the benefits are uncertain (Frankish and Horton, 2017).

1.2.2 Treatments for dementia

There is as yet no known cure for dementia, and whilst attempts have been made to find suitable pharmacological interventions to reverse or halt the course of dementia, they have been largely unsuccessful (Livingston *et al.*, 2017; Ahmed *et al.*, 2019; Jia *et al.*, 2019; Elia *et al.*, 2020). That said, there are pharmacological treatments which have clinically important effects on cognition, and psychological, environmental, and social interventions can help to delay progression of the disease and improve cognitive function, and that can assist in the management of behavioural and psychiatric symptoms (Buckley and Salpeter, 2015; Ahmed *et al.*, 2019). Western medical approaches utilise pharmacological and non-pharmacological treatment modalities in combination.

Pharmacological treatments

Pharmacological treatments are used to treat cognitive symptoms of dementia and to manage BPSD. Most of the medication is used to treat AD and LBD. The commonly prescribed medications for cognitive symptoms are Acetylcholinesterace inhibitors (ChEIs) such as Donepezil, Rivastigmine and Galantamine (Buckley and Salpeter, 2015; Ahmed *et al.*, 2019); that prevent breaking down acetylcholine enzyme in the brain.

Other medications including anti-psychotic, anti-depression and anxiolytic medications are commonly used to manage the BPSD such as psychosis, agitation, aggression, anxiety, depression or sleeping problems (Kales, Gitlin and Lyketsos, 2015). Buckley *et al.* (2015) stated that these medications can delay the memory loss, reduce worsening of the thinking process and attention for a few months in mild to moderate dementia but that they are not effective in severe stages, and are not effective as long-term treatments or for those aged over 85 years. Adverse effects of the medication such as weight loss, tremors, sleep problems and joint pains seem to outweigh the therapeutic benefits (Holmes *et al.*, 2008; Ahmed *et al.*, 2019).

Non-pharmacological interventions

With no effective pharmacological treatment available for most types of dementia, non-pharmacological or behavioural interventions have emerged as an alternative strategy to address BPSD, as well as to enhance the quality of life for the PwD and the caregivers. Most of such interventions help to improve cognitive and functional capacity of the affected person, enabling the ability of performing ADLs, or to address the related behavioural symptoms such as agitation, sleep disturbances, wandering or depression (Berg-Weger and Stewart, 2017). For example, music, dancing, swimming

or art therapy is used in combination with other treatments. Music therapy is a safe and effective method for treating agitation and anxiety in people with moderate and severe AD (Berg-Weger and Stewart, 2017; Woods *et al.*, 2018).

Application of psycho-therapeutic interventions such as reality orientation and/or reminiscence therapy are also reported in the management of dementia (Hall and Skelton, 2012). Reality orientation is a technique of presenting orientation information such as time, place and person-related information in order to provide an individual with dementia with a greater understanding of their surroundings, possibly resulting in an improved sense of control and self-esteem (Spector *et al.*, 2005). Reminiscence therapy includes discussion of past activities, memories or experience allowing the PwD to express thoughts and feelings. Activities may also use photographs or music to evoke memories and to stimulate conversations (Woods *et al.*, 2018). These therapies provide sensory stimulation, improve cognitive and behavioural outcomes including the ability to communicate and practice self-expression among the PwD (Spector *et al.*, 2005; Woods *et al.*, 2009, 2018). An action research study conducted in Japan revealed that cognitive rehabilitation is useful to restore lost procedural skills and help the elderly with dementia to regain confidence (Nomura *et al.*, 2009). There is also evidence for treatment methods such as the stem cell therapy and gene therapy for dementia (Svansdottir and Snaedal, 2006; Elia *et al.*, 2020). Most of these non-pharmacological interventions are reported to be useful in mild stages of dementia when used in combination with the medication (Kales, Gitlin and Lyketsos, 2015).

1.3 Dementia within an ageing world

1.3.1 Country classification in this thesis

According to new World Bank country classifications (2019 – 2020) countries over 12,375 US$ of Gross National Income (GNI) per capita are defined as HIC. Low and middle income countries (LAMIC) are further classified as upper-middle income countries (UMIC; 3,996 - 12,375 US$ of GNI/ capita) and lower-middle income countries (LMIC; 1,026 - 3,995 US$ of GNI/ capita; World Bank Data Team, 2019). Sri Lanka was a LMIC for dacades and since July 2019 newly assigned as an UMIC by the World Bank based on the country's GNI/capita (3,996 - 12,375 US$). According to the World Bank report income of Sri Lanka was 3,840 US$ GNI/ capita as of July 2018 and 4,060 US$ GNI/ capita as of July 2019 (World Bank Data Team, 2019).

I will use the same classification for the purpose of this thesis. However, when presenting arguments, despite their income levels, certain countries will also be grouped together based on their region, health systems and care models, socio-cultural, political or religious contexts throughout the thesis. For example, Thailand, Japan and Sri Lanka may group together as Bhuddist, Asian countries; China, India and Sri Lanka may be grouped together as countries that widely practice alternative or complementary treatment or healing methods for mental illnesses. In addition, I will also use the terms 'westernised' or 'western' when discussing the health and care models that are influenced by the cultural, economic, or political systems of Europe and North America.

1.3.2 Ageing

Nearly 900 million people of the world population are aged 60 years and over (ADI, 2015). Most developed countries have accepted the chronological age of 65 years as a

definition of an older person (WHO, 2010; Nikmat, Hawthorne and Al-Mashoor, 2011). However, the United Nations accepted the age of 60 years and above as the cut off to refer the older adults (Satharasinghe, 2016) and this age cut off will be used for the purpose of this thesis. As a result of demographic transitions, scientific advances in medicine and the availability of healthcare facilities for older adults, mortality rates have fallen and continue to fall; life expectancy is thus increasing worldwide (ADI, 2014; Prince et al. 2013). Aligned to this increase in life expectancy is a fall in fertility rates thereby increasing the overall proportion of older people, of total population, in most countries. This trend is accelerated more so in LAMIC when compared with the HIC (Prince *et al.*, 2013; WHO, 2018a). Over one-third of the current world population of older adults live in LAMIC (Prince, 2000; de Silva, Gunatilake and Smith, 2003; Wijeratne, 2015). To illustrate this difference between HIC and LAMIC, between 2015 and 2050, the number of older adults living in HIC is estimated to increase by 56%, compared with 138% in UMIC, 185% in LMIC, and by 239% in low income countries (ADI, 2015). As people age, the risks of disability and developing chronic, non-communicable diseases, including dementia, increases (Wu *et al.*, 2013; ADI, 2015; WHO, 2018b).

1.3.3 Incidence, prevalence and impact of dementia around the world

As a result of the global rise in life expectancy, dementia has become a major global health concern; it is considered to be one of the most burdensome conditions of later life and many older adults will experience and live with dementia in the future (WHO, 2018b). For example, the Alzheimer's Association recently reported the likelihood ratio of prevalence of AD is 15 percent in those aged 65 - 74 and 44 percent in those

aged 75 - 84. Out of the diseases labelled as a global burden, dementia contributes to 11.2 percent of disability in people aged 60 years and older (WHO, 2015), more so than many other conditions (e.g. stroke, musculoskeletal disorders, cardiovascular diseases and all forms of cancer). The ADI (2015) estimated that 36 million people around the world were living with dementia in 2010, and that the numbers may double every 20 years (i.e., 66 million by 2030 and 115 million by 2050).

Globally, a new case of dementia is found every 3.2 seconds, with 9.9 million new cases detected in 2015 (world report 2015). Approximately 46.8 million people worldwide were living with dementia in 2015 (Prince, Ali, *et al.*, 2016). When compared with previous, the WHO and ADI reports, these new estimates are almost 30% higher than the annual number of new cases estimated for 2010 (7.7 million new cases, one every 4.2 seconds) (WHO, 2012). There is evidence that prevalence has increased in Asia and Africa, but stabilised in Europe and the America (Kalaria *et al.,* 2008; ADI, 2015; Prince *et al.*, 2016; Satizabal *et al.*, 2016). A systematic review reports an increasing dementia prevalence in East Asia, consistent with worsening cardiovascular risk factor profiles (Prince *et al.*, 2016). It must be noted that most of the prevalence data is 'provisional' due to lack of evidence from many LAMIC (Patel and Sumathipala, 2001; Patel and Shaji, 2010; Jia *et al.*, 2019); especially South and East Asia, (Ferri *et al.* 2005; Prince *et al.* 2013; Nichols *et al.*, 2019; Hossain *et al.*, 2020), and may actually represent an underestimation in these settings.

Impact of Dementia

The direct and indirect impact of dementia can be categorised under three inter-related levels: the PwD, family and friends of the PwD, and the wider society. Dementia is the commonest mental illness among older adults (Prince *et al.*, 2015); for example,

it is the leading cause of death in the UK (Department of Health, 2013). In terms of years lived with disability and years of life lost, dementia is considered as a global burden (Ferri *et al.*, 2005; Shah *et al.*, 2016).

Dementia has an impact on disability-adjusted life years (DALYs- a measure of overall disease burden, expressed as the number of years lost due to ill-health, disability or early death) and quality-adjusted life years (QALYs- a measure of years lived in perfect health gained) of the PwD. The individual needs constant care and support with ADL over the course of illness. The tasks include intimate activities such as feeding, bathing, transferring, dressing, grooming, work, cleansing after defecating and other activities associated with financial and legal decisions (Miyamoto, Tachimori and Ito, 2010). Kales *et al*. (2015) stated that the BPSDs are among the most complex, stressful, and costly aspects of care, and that they lead to significant burden and responsibility for family caregivers. It is reported that impairment in orientation, communication, financial, and transportation skills in PwD are associated with negative impacts including burden and greater hostility among caregivers (Razani *et al.*, 2007, 2014).

The informal caregivers play a vital role in dementia care with the global focus of managing dementia in the community or home-based care settings. While informal caregiving results in better patient management and lower resource utilisation for the healthcare systems, there is a global narrative around the significant burden of long-term care and also the issues and challenges that informal caregivers are facing (Etters, Goodall and Harrison, 2008; Ornstein, 2011; De Vugt and Verhey, 2013; Villapando, 2015; Vaingankar *et al.*, 2016; Sutcliffe *et al.*, 2017). The impact of dementia on informal caregivers will be discussed further in Chapter Two.

Dementia creates a considerable economic and social burden (WHO, 2018b) in terms of treatments, health care use, professional care, informal care provided by family and others in primary care settings, the community and residential care, social care, and costs of lost productivity (ADI, 2014; Shah *et al.*, 2016). Evidence from surveys conducted by the 10/66 Dementia Research Group (DRG) in Latin America and China reported that the cost of dementia exceeded that of other conditions such as depression, hypertension, diabetes, ischaemic heart disease and stroke (Kalaria *et al.*, 2008; Prince *et al.*, 2012; Jia *et al.*, 2019). Most South Asian countries are heavily dependent on informal care provision by families (Wang *et al.*, 2014; Thirthalli *et al.*, 2016). The WHO reports challenges faced by the family caregivers in LAMIC is greater when compared to HIC mainly due to lack of financial, professional and social resources to meet the increasing care needs of PwD (ADI, 2015; WHO, 2018b).

1.4 Dementia care: an overview

As discussed above, it is clear that there is an increasing need to address the management of dementia, with particular emphasis on providing long-term care. PwD experience gradual deterioration which often results in a high level of dependency over the course of illness; therefore, the complexity of care needs required may vary from person to person (Kales, Gitlin and Lyketsos, 2015). The professional care including most of the therapeutic interventions for PwD mentioned in section 1.2 are provided in formal and primary care settings; however, a significant proportion of home-based, long term dementia care is provided by informal caregivers (Kaufman *et al.*, 2010; Stephan *et al.*, 2018). For example, in the United Kingdom (UK), about 60 to 70 percent of PwD reside in the community and are not subject to formal care services

such as psychiatric consultations (Jutlla, 2013b, 2015a), but they still receive social care and regular carer visits (Pink *et al.*, 2018). According to WHO, caring for PwD must be a collective effort that involves both formal care based in hospitals, community, primary or public health settings and informal, home-based care which is provided by the family members (WHO, 2012).

Challenges and burden that informal caregivers are facing is considered as a universal issue globally (Bremer *et al.*, 2015; Sutcliffe *et al.*, 2017). Much research has been conducted worldwide on psychological and physical wellbeing of informal caregivers (Boots *et al.*, 2014, 2015; Bremer *et al.*, 2015; Pendergrass *et al.*, 2015; Vaingankar *et al.*, 2016; Oh *et al.*, 2019; Parkman, 2019). This will be described in detail in Chapter Two, Section 2.13.

1.5 Cultural and social differences in dementia care

As seen above, there is a growing global demand on resources (both formal and informal) to ensure effective treatment, management, and care for those with dementia, which brings about certain challenges. Values, beliefs and attitudes towards religion, culture, and society have a great influence on the conceptualisation of dementia as well as the experience of caregiving for those with dementia (Brodaty, Green and Koschera, 2003; Chan, 2011; James and Peltzer, 2012; Keating, Long and Wright, 2013; Schoonover *et al.*, 2014; Xiao *et al.*, 2014; Thirthalli *et al.*, 2016). Most of the research evidence on dementia care emanates from a 'western-centric' perspective (Tremont, 2011; Hughes, 2013; Johnson *et al.*, 2013; Klein, 2014) and mainly considers dementia as a medical condition contextualised within a Caucasian/Christian approach to formal and informal care practice, with only a small portion of research

focused on ethnic-minority groups, which are also often situated within a HIC and/ or westernised setting (Jutlla, 2013a, 2013b, 2015b; Hossain *et al.*, 2018).

People from different social, cultural, economic and political domains define, experience and interpret dementia and aspects associated with dementia care in different ways (Sethabouppha and Kane, 2005; Wang *et al.*, 2014; Hossain *et al.*, 2018). For example, previous research conducted in the UK with South Asian dementia family caregivers has reported problems with both access to, and use of, health and social care services due to cultural and language barriers within existing services (Jutlla, 2015; Hossain *et al.*, 2018). Systematic reviews have revealed poor understanding and awareness of dementia among ethnic minority groups living in HIC as well as people in other regions including South Asia (Kalaria *et al.*, 2008; Jutlla, 2013b; Hossain *et al.*, 2018). Systematic reviews of ethnic differences in the use of dementia treatment and care has reported a reluctance among ethnic minority groups living in HIC to use dementia services such as the use of medication, memory clinics, screening and community social services (Cooper *et al.*, 2010; Sayegh and Knight, 2013). Many Chinese and South Asian people consider dementia as an act of God, while African or Anglo Americans consider it as a result of worry and stress (Wilkinson and Milne, 2003; Krull, 2005; Schoonover *et al.*, 2014; Jutlla, 2015b; Hossain *et al.*, 2018). In comparison, the majority in western populations consider dementia as a group of symptoms that occur when brain cells stop functioning properly, thus subscribing to the medical model (Sayegh and Knight, 2013).

Studies have also shown significant differences in the models of care and how caregivers perceive the caregiving role for those with dementia in other countries that are outside of the Western centric sphere (Sethabouppha and Kane, 2005; Pattanayak

et al., 2010; Wang *et al.*, 2014; Wijeratne, 2015). In many Asian countries, older adults are accorded great respect, both within the families and in society (Gupta and Pillai, 2002; Kalaria *et al.*, 2008; Shaji, 2009; Wang *et al.*, 2014; Ali and Bokharey, 2015; Jutlla, 2015b). In most situations, the elderly people live with their loved ones and therefore caregiving is viewed as the family's responsibility (Dilworth-Anderson and Gibson, 2002; Shaji, 2009; Chang, 2010; Patel and Shaji, 2010; Chan, 2011; Chen *et al.*, 2014). In some countries such as China, Nepal, India, Sri Lanka and Vietnam, caring for older people is assigned to family members by law as a mandatory requirement (Wang *et al.*, 2014; UNFPA Report, 2017), which is cleary different from Westernised approaches.

In light of these cultural and contextual differences, research recommends the need for culturally appropriate services and support for dementia caregivers that respect individual values within a cultural context (Kalaria *et al.*, 2008; Nomura *et al.*, 2009; Wijeratne, 2015). It is also recognised that such cultural and social differences are not static; for example, the traditional (South Asian) family role of caring for elderly people is becoming less prominent due to rapid socio-economic and demographic changes in these countries. The change in the family unit from extended families to nuclear families, the rapid growth of internal migration for employment, improved educational, economic and social status of women and changes in gender-based roles are a few examples (Pattanayak *et al.*, 2010; Kim *et al.*, 2012; Wang *et al.*, 2014). In Singapore the family support received during old age has continued to fall from 13.5% in 1970, to 8.4% in 2000 and 6.4% in 2013 (Vaingankar *et al.*, 2016), whereas in China 31.8% of elderly are living in an 'empty nest' (Wang *et al.*, 2014). There is also a trend to employ formal caregiver services to look after old people as a substitute to family caregivers; however, this is restricted to those who are able to afford the cost.

Caregivers' thoughts, beliefs, values and assumptions also affect the process of informal caregiving (will be discussed further in Chapter Two, Section 2.4, pages 51-57) and these factors culturally influence the short-term and long-term care management of PwD (Dilworth-Anderson and Gibson, 2002; Schoonover *et al.*, 2014). Therefore, it is important to consider the cross-cultural contextual environment, with a greater understanding needed beyond Western-centric views, especially so where cultural contexts are in a period of change.

1.6 Dementia as a research priority in LAMIC

As outlined above, the nature of illness, disability, need for care and the socio-economic impact of dementia has made it a global research priority. According to the Global Forum for Health Research, in general there is a 10/90 disparity in health research, which means that, of the billions of money spent worldwide each year on health research and development, less than 10% is devoted to the health problems affecting 90% of the world's population (Global Forum for Health Research & World Health Organization, 2000; Patel, 2007). Further, the 10/66 dementia research group revealed that 66% of the PwD live in LAMIC, however only 10% of research into PwD emanates from these countries (Prince *et al.*, 2012).

Evidence on burden of dementia in the Asia-pacific region suggests an increasing prevalence and debilitating impact of dementia in Asian countries (ADI, 2014; Prince *et al.*, 2016). In comparison to the western world, there is disparity in care in most Asian countries. Lack of dementia research reflects a scarcity of research in most countries in South Asia. The rapidly ageing population (WHO, 2018a), increased prevalence of dementia in LAMIC (Prince *et al.*, 2016) and the fact that the evidence on dementia care including prevention and management is widely originating from the

research conducted in HIC or westernised settings (Patel and Shaji, 2010; Satizabal *et al.*, 2016), indicates that the research literature to-date may be under-representing the situation in LAMIC and Asian contexts due to ethnic and socio-cultural diversity in dementia care (Jutlla, 2013b; Frankish and Horton, 2017). Therefore, dementia is currently a research priority in LAMIC.

1.7 Sri Lanka: the context

Dementia is an under-researched area in the Sri Lankan context in particular (as describes in Chapter Three), hence the breadth and depth of dementia prevalence and its care in Sri Lanka need further exploration even though it is not the focus of current thesis. The current PhD contributes to only one aspect of aforementioned dementia research gap, which is the phenomenon of informal caregiving for those with dementia.

The purpose of this section is to provide an overview to the study context. Accordingly, the following is a description of key demographic and socio-cultural characteristics of Sri Lanka, including the prevalence and incidence of older adults and dementia. In order to better understand the context, an overview of the health care system in Sri Lanka in terms of general health, primary health, mental health and also alternative health care systems including the indigenous and traditional care systems are also provided.

1.7.1 Key population characteristics

Sri Lanka is an island in South Asia renowned for its natural scenic beauty and cultural heritage, with a history of a great civilisation of over two thousand years. It was known

as Ceylon before 1972, and due to its geographic location, Sri Lanka had a long history of international engagement from the time of ancient 'Silk Road' to the present.

The population of Sri Lanka is 21.3 million (DHS, 2016) and the annual growth rate is 1.1% (Central Bank of Sri Lanka, 2018). It is a multi-ethnic country; the majority of the population are Sinhala (74.9%) (and out of them 70.1% are Buddhists), while other ethnic groups consist of Sri Lankan Tamils (11.2%), Tamils of Indian origin (4.1%), Muslims (9.3%), Burghers and a few others (0.5%) including Malays, Chinese and indigenous people called 'Veddas' (DHS, 2016).

As per the Sri Lanka Demographics and Health Survey (DHS) in 2016, the crude birth rate is 15.6 per 1000 population and the crude death rate is 6.2 per 1000 population. The crude birth rate has declined during the last two decades; in 1998, it was 17.3% (DHS, 2016). Mortality rates are low and continue to decrease (Hsiao and Li, 2000). The proportion of population aged 60 years and above has increased from 6.6% to 12.4% between 1981 and 2012 in Sri Lanka. The median age of the population also has shifted from 21.4 years to 31 years during the same period (UNFPA Report, 2017). The steady decline of fertility, with the shifting of the median population age, indicate the ageing of the Sri Lankan population, and consequently, the need to anticipate an increase in the incidence of dementia. Therefore, dementia research has identified as a national priority (Samaraweera and Maduwage, 2016).

Sri Lankans have a life expectancy of 78.6 years for women and 72 years for men (DHS, 2016). Those aged 17 and under constitute 30% of the total, those aged 18-59 constitute 57.5% of the total population and those above 60 years in age are 12.5% (DHS, 2016). The overall dependency ratio of the country is 60.2%; the elderly dependency ratio is 19.8% (MoH, 2016a). The potential support ratio is 7.1%. Table

1.2 below describes the trends in population by selected age groups from censuses and surveys from 1981 to 2016.

Table 1.2: Trends in population by age groups (Sources: Censuses and Surveys, Sri Lanka 1981 – 2016)

Age Group	Census 1981	Census 2012	DHS[1] 1993	DHS[1] 2000	DHS[1] 2006-07	DHS 2016
Working age population (15 – 64 years) (%)	60.5	66.9	63.5	67.1	66.5	64.5
Elderly Population (60 years and above) (%)	4.3	7.9	6.1	7.2	7.5	10.1
Ratio of persons aged 65 and over to those aged 15 – 64 (%)	7.2	11.8	9.6	10.7	11.3	15.7
	[1] Excludes Northern and Eastern Provinces					

Of the three official languages in the country, Sinhala is the language of the majority (74%), and Tamil (18%) is mostly spoken by ethnic Tamils and Muslims. English was introduced during British rule and continues to be the official language of higher education at university level, in both public and private sector administration and in English medium schools. Approximately 10% of the population can speak English (Central Bank of Sri Lanka 2018).

1.7.2 An overview of the health care systems in Sri Lanka

General Health Care in Sri Lanka

The Ministry of Health (MoH) is responsible for the provision of comprehensive health services in Sri Lanka. Services include promotional, preventive, curative and rehabilitative health care to carry forward the objectives of the Health Master Plan under the Government of Sri Lanka (MoH, 2016). The general health system is enriched by a combination of Allopathic (Western medicine), Ayurveda, Siddha, Unani, Indigenous and Homeopathic medicine systems (MoH, 2016a). Western medicine is the most popular and mostly caters for the health care needs of the nation (Samarage, 2006; Senanayake *et al.*, 2017). There is an extensive network of health care institutes

and health care facilities across the country with easy access for service users (Hsiao and Li, 2000; Samarage, 2006). A health care institute can be found within 4.8km from home of every patient (MoH, 2016a). Provision of health care is mainly via government health care systems, which is a free service, though an out of pocket expenditure of 35% is seen within current health expenditure in the country (WHO, 2017). Ninety percent of inpatient care services are covered by the government sector, ten percent inpatient care and sixty percent of primary care covered by the private sector (MoH, 2016a). Individuals usually pay themselves for private consultations, as health insurance is not extensively available in Sri Lanka. Private consultation is common among high-income earners in Sri Lanka, which raises concerns regarding the affordability of health care (PwC, 2014).

The large hospitals comprise teaching or university hospitals, provincial general hospitals, district general hospitals and base hospitals, located in main cities in the country. The smaller hospitals include divisional hospitals and primary medical care units. Large hospitals have better resources in terms of specialist care, staff, the number of beds and specialist wards. Comparatively smaller hospitals have a smaller staff (mostly one doctor and few nurses), fewer beds and facilities. Therefore, considerable disparities are seen in the perceived quality and availability of public health care provision (Senanayake *et al.*, 2017). Consequently, patients tend to bypass their nearest public health care facilities in preference for tertiary level public hospitals with more facilities or in some cases to private hospitals, as the primary care system in Sri Lanka does not have a gate-keeping role. Due to this liberal imbalanced utilisation of primary and secondary level hospitals, long waiting lists and

overcrowding in the tertiary level government hospitals are seen often (Senanayake *et al.*, 2017).

Although the pool of human resources for health care in Sri Lanka has increased over the years, the skill mix still remains imbalanced with a lack of qualified specialists across all healthcare categories including medical, nursing and allied health professions (Samaraweera and Maduwage, 2016; Fernando, Suveendran and De Silva, 2017; Senanayake *et al.*, 2017). When compared to other countries in the region, health care institutions in Sri Lanka are resourced by a variety of health care professionals; however, there is a staff shortage in both government and private health sectors perhaps due to increased migrating of qualified staff for more lucrative opportunities abroad (Samarage, 2006; Central Bank of Sri Lanka, 2018).

Primary Health Care in Sri Lanka

Primary Health Care (PHC) system in Sri Lanka was established in 1926 (Uragoda, 1987). Primary health care in the public sector is delivered through two parallel streams providing universal health coverage; that is, curative health services and community health services. Curative services provide both hospitalisation and ambulatory care (Senanayake *et al.*, 2017). There is no formal general practice (GP) structure similar to the UK established in Sri Lanka. However, qualified primary care doctors provide consultation for people in the outpatient clinics in the hospitals, fulfilling a role similar to that of general practitioners in the UK.

Community health services are mainly focused on prevention and health promotion based on the health unit system known as 'Medical Officers of Health' or MOH areas. MOH areas are the smallest administrative units of the public sector managed by medical officers (Community Physicians), supported by public health field staff

including Public Health Nursing Sisters, Public Health Midwives and Public Health Inspectors. The preventative sector is considered to be Sri Lanka's best health care achievement, particularly for women's and children's health, environmental health and preventive care for most of the communicable diseases (Senanayake *et al.*, 2017).

However, the interventions for mental health problems and elderly care services are scarce in the primary care setting in Sri Lanka (Samaraweera and Maduwage, 2016). The WHO and MoH of Sri Lanka have reported a rising burden of non-communicable diseases, mental health problems and disease conditions in old age including dementia (Senanayake *et al.*, 2017). There is no developed speciality for old age psychiatry or elderly medicine in Sri Lanka. Latest economic statistics show that the management of non-communicable diseases consumes 35% of the current health expenditure in Sri Lanka (Central Bank of Sri Lanka, 2018).

Mental Health Care in Sri Lanka

Mental health services in Sri Lanka were limited to tertiary-care institutions such as the National Institute of Mental Health (NIMH), teaching hospitals affiliated to medical faculties, and provincial general hospitals in the country until very recently (Jenkins *et al.*, 2012; Fernando, Suveendran and De Silva, 2017). There was a significant treatment gap as there was no integration of mental health services in to the primary health care setting due to lack of awareness, the stigma associated with mental illness, lack of accessibility for services, as well as due to the poor continuity of care and management of treatment after discharging from the tertiary care units (Fernando, Suveendran and De Silva, 2017).

Mental health service expansion in Sri Lanka was identified as a priority in the WHO country co-operation strategies for the years 2012 – 2017 (WHO 2014). The main

focus areas were: training public health care professionals, strengthening the health information system and research capacities, and implementing a comprehensive community-based, decentralised mental health service structure (Fernando, Suveendran and De Silva, 2017).

Current mental health services delivered by trained professionals include service provision at the hospitals and outpatient clinics, domiciliary care, mental health promotion in schools, and community mental health education in collaboration within primary care setting (Fernando, Suveendran and De Silva, 2017). Fernando *et al.* (2017) report that community mental health nurses were trained and allocated to work across the country during the past two years. However, it appears that the mental health care services provided at the community level and domiciliary level are minimal and are ineffective due to the increased workload and inadequate staff numbers. The majority of medical officers (mental health) and qualified nurses are currently working in secondary-care institutions and some primary-care institutions such as divisional hospitals in Sri Lanka (Fernando, Suveendran and De Silva, 2017).

1.7.3 The indigenous medicine, complementary and alternative healing approaches in Sri Lanka

Indigenous medicine as well as complementary or alternative healing methods are widely practiced among people in Sri Lanka as a treatment method for both physical and mental illness (Uragoda, 1987; Broom *et al.*, 2010).

Indigenous medicine

Practice of indigenous medicine in Sri Lanka has a history of over 3,000 years. There are four main categories including; Ayurveda (or North Indian traditional medicine), Siddha (or South Indian traditional medicine), Unani (or medicine of Arabic origin)

and *Paramparika* medicine (Ancient local or *Desheeya Chikitsa*) (Uragoda, 1987). Ayurveda is the most commonly used category. It is reported that 60% to 70% of the rural population prefer Ayurveda treatments and there are over 400 Ayurveda hospitals across the country (MoH, 2016a). Indigenous medical practice is currently legitimate in Sri Lanka by Ayurveda Act No.31 of 1961, section 89. The indigenous medicine system in Sri Lanka has university affiliated formal course-based institutional training, and sometimes the training through apprenticeship from one generation to the other by the families famous for traditional medicine (Liyanaratne, 1996). In addition to traditional medicine, several other complementary methods such as yoga, aromatherapy, acupuncture and homeopathy are also available.

Complementary and alternative medicine

Apart from the categories mentioned above, alternative or faith-based healing methods are still widely practiced for mental health conditions in Sri Lanka. Most of these are based on religious and cultural beliefs. These methods include folk remedies and forms of self-care based on family values and culturally learned practices (Uragoda, 1987). The rituals can differ based on the religious, traditional and cultural beliefs of the individuals.

Astrological and planetary influences on illness, beliefs of spiritual healing and influence of Buddhism as the main religion have a strong connection with alternative medicine practices. Common practices include: invoking blessings from monks, religious and spiritual exercises such as *Pirith* chanting, mantra (incarnations of magical or sacred sounds imbued with power), wearing blessed threads and sanctified gems, offerings to supernatural spirits, the Gods, clergy and sometimes to animals, and various methods of devil dancing (called *Bali, Thovil and Shanthikarma*) used for

exorcism and healing (Simpson, 2007). Pranic and Reiki energy healing methods are also becoming popular. Different types of healing practices and rituals are conducted by experts or healers such as witch doctors, exorcists, devil dancers, drummers and other caste-based professionals, priests and monks sometimes in consultation with astrologers or clairvoyants. However, the professional bodies including Sri Lanka Medical Asociation (SLMA) and the government do not accept these alternative medicine practices and rituals as legitimate methods for treating illness. Despite this, most people (over 50%) seek these alternative and traditional healing methods as treatment for illnesses (Simpson, 2007).

1.7.4 Ageing and Dementia in Sri Lanka

Ageing in Sri Lanka

Section 1.3 discussed the global picture of ageing. Considering the situation in the Sri Lankan context specifically, currently over 2.5 million (12.5%) are aged over 60 years (DHS, 2016). Table 1.2, above, showed that the percentage of elderly people relative to the total population has doubled during the period from 1981 to 2016 (MoH, 2016). This number is estimated to increase further in the future with estimates of 16.7% by 2021 and 25% by 2041(Hsiao and Li, 2000; Wijeratne, 2015; Samaraweera and Maduwage, 2016). In the coming years Sri Lanka may experience the fastest ageing population in the region; these rates are expected to be more rapid than Japan, China and other South Asian countries (Hsiao and Li, 2000; Wijeratne, 2015).

This trend is attributed to epidemiological transitions, increasing education and awareness levels, elevated health care seeking behaviour, improvement of health and socio-economic conditions, easy access to health care and the end of the civil war (Hsiao and Li, 2000; PwC, 2014). Policies and initiatives to promote health and

wellbeing of older adults will be necessary and the country will face many challenges including planning health care, elderly oriented services, social care and community care for older adults (Samaraweera and Maduwage, 2016). The rising proportion of the aged population of Sri Lanka will alter the overall disease profile of the country and consequently affect the volume and type of services required. Samaraweera and Maduwage (2016) suggest the existing health infrastructure and systems require strengthening, reorientation and coordination, to meet the current and future health care needs of the growing elderly population. Accordingly, Sri Lanka's National Senior Citizens Charter and Policy 2006 includes provisions related to preventing discrimination, abuse, neglect and violence against older people (UNFPA Report, 2017); Sri Lanka's essential health services package has identified the importance of mental health and complex health care needs (including dementia) of the ageing population (MoH, 2019).

Dementia in Sri Lanka: Prevalence, Incidence and Impact

Mental health related information was not included in the Sri Lanka Demographic and Health Survey (DHS) until the year 2016. The Lanka Alzheimer's foundation has estimated that there may be at least 150,000 people (0.7%) with dementia living in Sri Lanka, and in 2050 that figure is estimated to rise to 463,000 (2% of total population) (Wijeratne, 2015, Lanka Alzheimer's annual report 2014/ 2015). In a recent report, the MoH Sri Lanka highlights that the dementia prevention measures should begin in early adulthood and severe cases require home-based nursing care (MoH, 2019). Compared to other South Asian countries, there is lack of evidence on dementia and caregiving for dementia due to low research output in Sri Lanka (Abeywickrema *et al*., 2015; Wijeratne, 2015). Information on health care services and facilities for PwD and

the caregivers, dementia treatments and public awareness on dementia is severely hindered in Sri Lanka due to the lack of research and evidence-based practices (de Silva, Gunatilake and Smith, 2003; Abeywickrema, Weerasundera and Ranasinghe, 2015). Despite this paucity of research, a few key studies have been carried out in this context and the findings of a systematic review carried out to explore evidence on dementia research activity in Sri Lanka is presented in Chapter Three.

Impact of demographic, social and economic transition on family caregiving in Sri Lanka

Sri Lanka is undergoing socio-economic transitions causing changes to traditional family units. Modern demographic and economic transitions such as industrialisation, urbanisation and new technology have brought about major changes in families and social structures in Sri Lanka there by weakening the traditional family support system and changing the traditional patterns of care giving in most families (Samaraweera and Maduwage, 2016). For example, due to increased labour migration and job opportunities for women, most of the older adult population play a role as caregivers for their grandchildren (Census, 2012). Some older adults are isolated once the children move out and there is a possibility of having to spend the later stage of their lives in care homes (Umayal *et al.*, 2010). A survey conducted in 2008 reports that only 13% of Sri Lankan elders felt they were receiving good emotional support from their family members. At the time, more than 70% of the Sri Lankan elderly population lived with either spouse or children; 13% of the older adults were either living alone without children's support or in elderly homes (Fernando, 2008). There has been an increase in the number of care homes for the elderly in Sri Lanka from a total of 68 homes in 1987 to 162 homes in 2003 (Annual Health Bulletin, 2006). However, due to socio-cultural influence, stigma and the lack of well-established community-based

health care systems or social support services for the elderly, institutionalised care is not popular and not-effective; most care homes currently do not provide 'dementia-friendly care' for the residents (Samaraweera and Maduwage, 2016), which includes care home environments that help PwD to live a life as independent and safe as possible, and provision of dementia specific care by trained staff, Given the evidence of the increasing elderly population and lack of services, this may represent a serious future problem. According to the Annual health bulletin (2016) the government of Sri Lanka has taken initiatives to developed elderly friendly services in some districts in order to improve mental and social wellbeing of older adults (MoH, 2016).

1.8 Rationale for the current study

As already highlighted, Sri Lanka is rated as the fastest aging population in South Asia and consequently, increasing the incidence of dementia (De Silva *et al.*, 2009; Umayal *et al.*, 2010; Wijeratne, 2015). The majority of studies on caregiving for those with dementia predominantly come from HIC, utilising westernised caregiving models. It may not be appropriate to utilise these caregiving strategies and care models in a culturally different Asian country like Sri Lanka. Evidence from different regions in the world shows differences in terms of dementia care services, perceptions of care professionals, carers and family members, and socio-cultural impact towards dementia caregiving. The differences within subgroups and cultures are to be expected as not all populations are homogeneous (Dwyer and Buckle, 2009). In this context, it is timely and relevant to look at whether differences do exist within different socioeconomic and cultural settings in terms of how the family members adapt the caregiving role, cope and react to the course of dementia from the onset of illness, and how being given a diagnosis of dementia affects the PwD and caregivers. Therefore,

the key focus of the current study is on Sri Lanka (an under-researched UMIC) where cultural differences and socio-demographic transitions may make dementia care quite different to HIC.

Given the increasing life expectancy and elderly population, rapid demographic transition, changing social structures, socio-cultural diversity and underdeveloped community and social care services for older adults in Sri Lanka (Abeywickrema *et al.*, 2015; Wijeratne, 2015; Samaraweera and Maduwage, 2016), it is important to pay greater attention to explore the aspects of informal dementia care in the context. However, current information and research on caregiver experience and understanding is lacking in Sri Lanka as with other LAMIC and South Asian countries (Hossain *et al.*, 2018). Hence, qualitative research is required to explore the caregiving experience of informal caregivers within the Sri Lankan context. This current study will be the first qualitative study that explores the views and experiences of informal caregivers for PwD in Sri Lanka.

1.9 Significance of the study

The study will explore views and experiences of informal caregivers for people with dementia and provide a deeper understanding of what it is like to live with and care for a family member with dementia, the family dynamics and changes to the lives of caregivers and other family members. Findings of this study will also explore gaps, similarities and differences in dementia care in the Sri Lankan context when compared to other Asian and Westernised settings, and provide insights for socio-culturally sensitive approaches to dementia care and management in an Asian UMIC like Sri

Lanka. Therefore, this study has significant cross-cultural value to Sri Lanka as well as to the South Asian region.

Furthermore, the findings will be a valuable reference in general for health care professionals and nursing and medical students; study outcomes will also contribute towards education purposes.

1.10 Structure of the Thesis

The structure of the thesis will be as follows. Chapter Two will review and evaluate previous research evidence relevant to dementia caregiving. This chapter will describe the concepts in the existing literature in relation to dementia care and caregiving for dementia in different contexts. This includes a review on existing dementia care models, informal caregiving and the impact of dementia on caregivers. Chapter Three will report findings of a thorough literature review on dementia research activities in Sri Lanka. Research question, aim and objectives are detailed at the end of Chapter Three. Chapter Four outlines the methodology for the study; including, the theoretical approach, study design and ethical considerations. Methods of data collection and data analysis will also be described.

Findings will be split over several chapters describing the themes emerging from data analysis. Chapter Five will present the demographic information of the study participants; chapters six, seven and eight will address the three 'super-ordinate themes' that emerged from the data. Accordingly, Chapter Six will describe the meaning of dementia, Chapter Seven will describe the meaning, practice and purpose of caregiving from the view point of informal caregivers. Chapter Eight will present the caregivers' concerns, challenges and support needs in relation to caregiving.

Chapter Nine presents a discussion of the key findings, recommendations, implications and conclusions of the study. Findings from the three analytic chapters will be brought together and discussed within the context of relevant research literature. There will be a section that discusses the strengths and limitations of the study including the challenges, and the ethical concerns that arose during the overall research process.

I will also reflect upon the experience of my PhD journey as a bi-directional learning opportunity for capacity building at various stages in this chapter. I will describe my research experience, the impact of numerous skills obtained as a PhD scholar including sharing of knowledge through exposure to various learning opportunities, mentorship and training in the UK and during the data collection process in Sri Lanka.

Chapter Two

Dementia caregiving: an overview

Chapter One provided an overview of dementia, a description of the study context, the rationale and significance of the study. This chapter presents an overview which was carried out using the academic databases in order to evaluate the conceptual and empirical literature which led to the development of the research question, aims and objectives of this thesis. This chapter also outlines the current key constructs that describe the experience of caregiving for people with dementia (PwD) by exploration of the existing dementia literature. Accordingly, evidence on dementia caregiving, the impact of dementia on informal caregivers, dementia care models and services, and support systems currently available for dementia caregivers will be described. There is also a comparison of similarities and differences of dementia caregiving among high-income countries (HIC) and low and middle-income countries (LAMIC) with a particular focus on South Asian regions, with a narrowing of focus to a Sri Lankan perspective in line with the central analysis of this thesis.

2.1 Dementia care

Health care provision for PwD is a continuous, holistic and integrated process. Dementia care includes aspects such as diagnosis, treatments, formal health care use, informal caregiving, community care, residential care and social care (Prince *et al.*, 2009; Cahill, Shea and Pierce, 2012; ADI, 2014; Vaingankar *et al.*, 2016). Provision of care for PwD can be either formal or informal. The WHO reports that integration between formal and informal sectors provides optimal care for PwD (WHO, 2018b).

2.1.1 Formal dementia care

Formal dementia care is provided by trained health care professionals (HCP) and dementia care teams in hospitals, primary care, day care services, acute and residential care settings, and community or long-term medical and social care structures such as respite services (Stephan *et al.*, 2018). Formal caregivers include a range of HCP; particularly geriatricians, gerontologists, old-age psychiatrists, general practitioners, dementia nurses, community workers, social workers and support care workers (Jansen *et al.*, 2009). Care roles and tasks of HCP and support workers are designed to ensure optimal delivery of services to meet the health and social care needs of PwD and their family caregivers (Traynor, Inoue and Crookes, 2011).

2.1.2 Dementia Care models

There are many dementia care models which guide the formal practice of care. In general these care models provide guidelines and recommendations for the provision of formal care for local and international practice (Tremont, 2011; Hughes, 2013; Johnson *et al.*, 2013; Klein, 2014). Among them, there are biomedical models, social models, bio-psycho-social models (which also includes environmental-spiritual models) and newer approaches such as the compassion model (Moore *et al.*, 2017). Following is a description of care models commonly practiced in formal dementia care.

The bio-medical model

The bio-medical model frames dementia as a disease caused by biological factors and excludes other influences such as psychological, environmental, and social factors. Chapter One, Section 1.2 described the management of dementia including two main approaches; pharmacological management to slow the condition and symptom progression, and non-pharmacological interventions to manage symptoms such as

behaviour and psychological symptoms of dementia (BPSD). The bio-medical approach is widely practised within formal health care systems in both HIC and LAMIC (Nolan *et al.*, 2004; Prince *et al.*, 2009; Barker and Board, 2012).

Person-centred care model

The person-centred care model is underpinned by the philosophy of personhood; it does not also include medical management, but takes account of other factors as well as part of a more holistic approach (Hughes, 2013). In his book 'Dementia reconsidered' Tom Kitwood (who conceived the notion of person-centred care in dementia) writes:

'Personhood is a standing or status that is bestowed upon one human being, by others, in the context of relationship and social being. It implies recognition, respect and trust.'

(Kitwood, 1997: p.8)

Person-centred care considers PwD as individuals responding to their unique needs, which will not follow a set of criteria. Therefore, the person with dementia (PwD) comes first during the caregiving process which:

'…brings into focus the uniqueness of each person, respectful of what they have accomplished and compassionate to what they have endured. It reinstates the emotions as the well-spring of human life and enjoys the fact that we are embodied beings. It emphasises the fact that our existence is essentially social.' (Kitwood 1997: page 135)

The acronym 'VIPS' suggested by Brooker (2007) encapsulates the broader meaning of person-centred care: PwD and their caregivers must be **V**alued; they must be treated as **I**ndividuals; the **P**erspective of the PwD must be understood, and the person's **S**ocial environment must be considered when attending to care needs as relationships are

important in sustaining personhood. Person-centred care focuses on individual care needs and rights of the PwD; it does not emphasise the medical management or aspects of end of life care (Hughes, 2013).

Relationship-centred care model

Nolan *et al.* (2004) developed a 'relationship-centred care model' called 'the senses framework' for PwD and their formal and informal caregivers. This model suggests that the formal caregivers are in a relationship with PwD and their family members in order to understand their care needs according to their psycho-social, environment and cultural context rather than only focusing on person-centred care approach. This model also facilitates palliative care and supportive care for PwD as well as their caregivers from the onset of dementia until the death of PwD (McCormack, 2001; Ames *et al.*, 2013; Hughes, 2013). This model also suggests the PwD, family caregiver and the HCP need to experience relationships that promote 'six senses' when providing care for the PwD: security, belonging, continuity, purpose, achievement and significance (Nolan *et al.*, 2004). The experience of the PwD is virtually absent in the existing literature because of assumptions about the validity of self-report (Kolanowski *et al.*, 2018). In this context, the senses framework provides better understanding of important aspects of dementia care inclusive of concerns of formal and informal caregivers and also PwD (Nolan *et al.*, 2004).

Family nursing care model

Family nursing is suggested as a much broader approach than person-centred care and relationship-centred care. People's experience of living with dementia and the provision of care arises through reciprocal relationships and participative activity (Adams, 2008). Therefore, a bio-psychosocial approach is required to understand the

subjective experience of living with dementia and caregiving in order to appropriately target interventions and provide support for PwD and their family caregivers. The family nursing model addresses both formal and informal care needs including biological, psycho-social and environmental concerns of PwD and their family. The model also addresses the concerns of formal health and social care systems, voluntary services that contribute to dementia care provision. For example, 'The eight pillars model of community support for dementia' provides a coordinated approach to support long term home-based care for PwD and their informal caregivers in Scotland (Kinnaird, 2010; Rodgers, 2016). The eight pillars model covers a full range of factors that influence the experience and impact of dementia caregiving. These factors include dementia practice coordination, therapeutic interventions to manage BPSD, treatments for general and mental health care, personalised support for PwD and caregivers, as well as facilitating care environment and community connections (Kinnaird, 2010). With the empirical evidence on universal challenges and burden that informal caregivers are facing (Boots *et al.*, 2014, 2015; Bremer *et al.*, 2015; Pendergrass *et al.*, 2015; Vaingankar *et al.*, 2016; Sutcliffe *et al.*, 2017; Oh *et al.*, 2019; Parkman, 2019) family nursing care models are more appropriate for long-term dementia management.

The compassion model for end of life dementia care

Many countries including westernised HIC have incorporated a compassion-based and a 'bio-psycho-social-environmental-spiritual' approach to long-term dementia care. The compassion model describes a compassion based intervention for intergrated care for people with advanced dementia who spend their end of life in nursing homes (Moore *et al.*, 2017). According to the European Association for Palliative Care (EAPC)

optimal care for those who are approaching death includes 57 recommendations which include aspects of person-centred care, interventions and shared decision-making with the PwD and their family members (van der Steen, Radbruch and Hertogh, 2014). There are two core components of this intervention based model: (1) facilitation of an integrated, multidisciplinary approach to assessment, treatment and care, and (2) education, training and support for formal and informal care givers (Moore *et al.*, 2017). Accordingly, this care model addresses the physical, psychological, emotional and social needs of the PwD and also training sessions for formal caregivers, education and support for nursing home and family caregivers.

2.1.3 Informal dementia care

Existing literature reports that most PwD live in the community and are cared for by unpaid informal caregivers (Nikmat, Hawthorne and Al-Mashoor, 2011; Thyrian *et al.*, 2017; Kolanowski *et al.*, 2018). Informal dementia care includes the provision of most of the day-to-day care of PwD in a home-based care setting, mostly provided by un-paid, untrained individuals, usually the family members, relatives or friends (Orpin *et al.*, 2014). Studies show that, as the population ages and prevalence of dementia increases, the health care industry has placed greater emphasis on home-based care in an attempt to contain costs associated with long-term and palliative care (Verbeek *et al.*, 2012; Banerjee, 2013; De Vugt and Verhey, 2013; Alzheimer's Association, 2015). As described in Chapter One, due to memory deficits and BPSD, PwD require long term, individualised, round-the-clock care as the disease progresses (Mace and Rabins, 2017). Therefore, home-based informal care is encouraged and considered efficient when compared to care provision in a hospital setting (Kinnaird, 2010; Nikmat, Hawthorne and Al-Mashoor, 2011; Orpin *et al.*, 2014; Stephan *et al.*, 2018).

2.2 Informal caregiving for people with dementia

Caregiving for a PwD is a subjective experience; it is influenced by many factors, including the individual circumstances, personal characteristics of individual caregivers, PwD's BPSD, the severity of dementia and the care situation (Lin, Macmillan and Brown, 2011). The prominent focus of this thesis is on informal caregiving for PwD; therefore, the literature review is also narrowed down to focus on informal caregiving. Informal caregiving refers to 'activities and experiences involved in providing help and assistance to relatives or friends who are unable to provide care for themselves' (Pearlin *et al.*, 1990).

2.2.1 Informal caregivers

Informal caregivers are unpaid individuals (that is; close family members or emotionally and spatially proximal individuals) who provide regular, on-going assistance to another person, perhaps a family member, friend, relative or a neighbour who is dependent or requires support because of age, physical or other disability such as chronic incapacitating illness or injury (Nolan, Grant and Keady, 1996; Foizie, 2012; Orpin *et al.*, 2014; Abeywickrema, Weerasundera and Ranasinghe, 2015). Informal caregivers make a major contribution to dementia care (Reinhard *et al.*, 2008; Kim, 2013; Ducharme *et al.*, 2014; Wang *et al.*, 2014; Chiao, Wu and Hsiao, 2015; Wijeratne, 2015); most of them are women (Prince, 2004; Ducharme *et al.*, 2011; Alzheimer and Association, 2014; Gibbons *et al.*, 2014; World Health Organisation, 2015), among them the majority are spouses and children of PwD (Szapocznik, 2008; Conde-Sala *et al.*, 2010; Kim, 2013; Reamy *et al.*, 2013; Shim *et al.*, 2013; Ducharme *et al.*, 2014; Gibbons *et al.*, 2014; Xiao *et al.*, 2014; Borsje *et al.*, 2016).

In the UK one in three people cares for a PwD in their lifetime (Newbronner, 2013); hours of care provided by the informal caregivers accounts for 55% of all dementia care provided in the community in Scotland (Monaghan, 2013). In Canada 80% of community-based dementia care is provided by unpaid caregivers (Jansen *et al.*, 2009). Evidence indicates that most of the dementia care is provided by informal caregivers in LAMIC (Connell and Gibson, 1997; Prince, 2004; Sethabouppha and Kane, 2005; Pattanayak *et al.*, 2010; Chan, 2011; Chen *et al.*, 2014; Wang *et al.*, 2014; Ugargol *et al.*, 2018).

2.2.2 Role of the informal dementia caregivers

In comparison to the formal care models outlined above, the role of the informal caregiver is poorly defined, and is often unrecognised and unacknowledged as a role even by caregivers themselves (Jarvis, 2012; Orpin *et al.*, 2014). The types of activities and level of support provided by the informal caregivers are dependent upon the severity of dementia, specific needs of PwD and the changes that often occur as the illness progresses (Brown and Brown, 2014; Stephan *et al.*, 2018). Caregiving tasks can include assisting with activities of daily living (ADL, such as bathing, dressing, feeding, toileting or managing incontinence), managing BPSD, giving medication and monitoring other treatments. Caregiving tasks may also include meal preparations, shopping, providing transportation, ensuring safety, managing finances and legal issues of PwD (Wang *et al.*, 2014; Meyer, Cullough and Berggren, 2016).

Due to the usually slow progression of dementia, most informal caregivers spend many years in the caregiving role. For example, a quantitative study from the USA on dementia caregiving outcomes reports that 32 percent of informal caregivers had been providing care for a person with Alzheimer's Disease (AD) for a period of five years or

more, and within that group, 12 percent have been providing care for 10 years or longer (Nikzad-terhune, 2011). Hoefer (2009) states that average life expectancy in dementia is between 5 to 9.3 years; however, this can range between one to 15 years depending on the cause, severity of dementia and when it is diagnosed.

Informal caregivers play a vital role in contributing to the health care system, especially in supporting PwD to remain in their homes and communities and out of residential care (Gitlin, 2012; Orpin *et al.*, 2014; Lee *et al.*, 2019). There have been found to be significant benefits of informal caregiving for PwD in terms of patient outcomes such as better patient management, and significant lower resource utilisation for health care systems (Cohen, Colantonio and Vernich, 2002; Nikmat, Hawthorne and Al-Mashoor, 2011; Oh *et al.*, 2019; Willis *et al.*, 2020).

Several studies report negative consequences following institutionalisation of PwD, including increased loneliness, alienation, depression, decrease in functional abilities and death (Gaugler *et al.*, 2005; Davis *et al.*, 2009; Verbeek *et al.*, 2012; Sun *et al.*, 2013; Afram *et al.*, 2014; Briggs *et al.*, 2017). Evidence suggests that care home placement of the PwD is one of the most difficult decisions made by the family caregivers (Nikmat, Hawthorne and Al-Mashoor, 2011; Sun *et al.*, 2013). A recent study revealed that family caregivers perceive formal care as a threat to the independence of PwD and therefore, avoided using formal care as long as possible (Stephan *et al.*, 2018). Nursing home placement for PwD is influenced by many factors such as impact of the caregiving experience (e.g. sense of burden and frustration), increased advanced care needs during late stages, and when the caregivers perceive they cannot provide the care the PwD deserve at home any longer (Etters, Goodall and Harrison, 2008; Afram *et al.*, 2014; Sutcliffe *et al.*, 2017). In addition, family dysfunctions, decreased social

support, fewer contacts with the PwD due to work or not living in the same household, female gender of the caregiver and lesser influence of cultural and religious practices on caregiving (e.g. stigma) influenced the tendency for seeking institutionalised care (Etters, Goodall and Harrison, 2008; Bunn *et al.*, 2012; Afram *et al.*, 2014). Caregivers reported experiencing guilt and frustration when they had to place their loved one in nursing homes (Butcher, Holkup and Buckwalter, 2001; Peacock, 2013).

2.2.3 Impact of dementia on informal caregivers

Diagnosis of a family member with dementia has a significant impact on the family (Cooper *et al.*, 2010; De Vugt and Verhey, 2013; Mace and Rabins, 2017; Lee *et al.*, 2019; Oh *et al.*, 2019). Evidence shows many similarities in the individual's experiences of becoming a dementia caregiver regardless of culture and context (Chan, 2011; Bunn *et al.*, 2012; Lee *et al.*, 2019). For example, experiencing psychological distress, changes in relationships with family members, family conflicts, depressive symptoms are commonly reported (Lee *et al.*, 2019; Oh *et al.*, 2019). Dementia diagnosis can often lead to families feeling overwhelmed, followed by a number of potential consequences (which affect both physical and psychological wellbeing) for the PwD as well as the members of the family (Brodaty and Donkin, 2009). PwD may struggle to preserve aspects of their former selves; experiencing a sense of anger, confusion and loss of identity (Bunn *et al.*, 2012), while the caregivers experience a feelings of loss, uncertainty, stress, burden, guilt and frustration (Etters, Goodall and Harrison, 2008; Bunn *et al.*, 2012; De Vugt and Verhey, 2013). Mace and Rabins (2017) report that the caregivers find it difficult to cope with role changes and having to learn new skills and responsibilities when a family member developed dementia. Despite the clear benefits of long-term care within informal settings, caregiving for dementia

has been described as a very demanding and a complex task for family caregivers (Mace and Rabins, 2017).

In a grounded theory study, Lin *et al.* (2011) highlighted that the process of caregiving and experience of living with the PwD may affect the lifestyles, health and wellbeing of the rest of the family members. In this study by Lin *et al.* (2011), family caregivers reported that their life changed at the beginning of the caregiving journey due to the commitment, duty and responsibility of caregiving. The caregiver's life can often become restricted by the act of caregiving (i.e., role captivity) as care may involve commitment over many years (Mace and Rabins, 2017; Parkman, 2019). The time spent on caregiving increases as the severity of dementia increases (Etters, Goodall and Harrison, 2008). Family caregivers may give up employment and have less time for self, children and the rest of the family members as a result of increased responsibility and full-time commitment to care (Chan, 2011; Tremont, 2011; Zwaanswijk *et al.*, 2013; Wang *et al.*, 2014). Most family caregivers are not trained to care for the patient; nevertheless, they occupy a full-time caregiving role with little chance of respite, often involving '36-hour day' supervision (due to increased workload, responsibility and the burden associated) according to Mace and Rabins, (2017). The most difficult and demanding aspects of care have been found to include managing the BPSDs, the person's dependency and resistance to care (Gitlin, 2012; Wang *et al.*, 2014; Meyer *et al.,* 2016).

Lack of awareness regarding the nature of the illness, lack of caring skills, caregivers' attitudes associated with stigma, blame and lack of psychological support cause distress for caregivers and can also lead to depression (Etters, Goodall and Harrison, 2008; Kim *et al.*, 2012; Ducharme *et al.*, 2014). The term 'caregiver burden' is most

often used to describe this phenomenon. Caregiver burden is defined as 'the degree to which caregiver's emotional or physical health, social life or financial status had suffered as a result of caring' for PwD (Zarit, Todd and Zarit, 1986; Etters, Goodall and Harrison, 2008). Systematic reviews on caregiver burden reveal that caregiver-related factors (e.g. age, gender, educational level, personal beliefs, values and attitudes and relationship with the PwD) as well as patient-related factors (e.g. type of dementia, severity, extent of behaviour and personality changes and presence of psychiatric symptoms) are associated with caregiver burden (Etters, Goodall and Harrison, 2008; Chiao, Wu and Hsiao, 2015). Evidence shows that the caregivers experience both objective and subjective burden (Chatterjee, 2008; Etters, Goodall and Harrison, 2008; Chiao, Wu and Hsiao, 2015; Ugargol *et al.*, 2018). Objective burden refers to the caregiver's behaviour with regard to the tasks of caregiving, socio-demographic characteristics (e.g. gender, income, education, cohabitation with the PwD and ethnicity), as well as the changes in household routines, work, family and social relationships, leisure time and physical health (Kim *et al.*, 2012). Subjective burden relates to either perceived or externally evident psychological distress of the caregivers (Cao and Yang, 2020).

The sense of burden negatively affects caregiving activities, seeking treatment or care support and the responsibilities of the family caregivers (Lee *et al.*, 2019). Caregiver burden can negatively affect the quality of life of the caregiver (Villapando, 2015; Jennings *et al.*, 2016) and lead to other life-changing effects such as disruptions to sleep, physical illnesses, strain, depression and social isolation (Vellone *et al.*, 2008; Beinart *et al.*, 2012; Parkman, 2019). Caregivers' own physical and emotional health is often neglected as they struggle to meet the demands from their own work, household

responsibilities and caregiving (Chan, 2011). Caregiver burden and distress also have negative consequences on patient outcomes due to increased possibility of abuse of the PwD by the caregiver, early entrance into formal care settings, and early mortality due to poor quality of caregiving (Brodaty *et al.*, 2003; Prince *et al.*, 2007; Golden *et al.*, 2012; Prince *et al.*, 2012; Reamy *et al.*, 2012; Kim, 2013; Ducharme *et al.*, 2014; Wang *et al.*, 2014; Abeywickrema *et al.*, 2015).

It is also widely reported that the caregiver burden tends to increase in association with greater severity of dementia (Diwan, Hougham and Sachs, 2004; Tremont, 2011; Beinart *et al.*, 2012; Lin, Macmillan and Brown, 2012; Wang *et al.*, 2014; Chiao, Wu and Hsiao, 2015). Another important aspect of increased caregiver burden is the lack of support received by the caregivers from PwD, family members or professionals (Caserta *et al.*, 1987; Diwan, Hougham and Sachs, 2004; Cooney, Howard and Lawlor, 2006; Wang *et al.*, 2014). Therefore, caregiver burden has health care resonance and most national and global strategies on dementia management are based on the concept of improving patient outcomes and minimising caregiver distress (WHO, 2018c). There has been an emphasis in the literature on understanding the psychological and physical effects of caregiving and assessing the needs of caregivers in order to help them to cope with the burden of caregiving (Flynn Longmire and Knight, 2011). Mace and Rabins (2017) highlight that responsibility of caregiving is often not evenly shared among the family members, those who do not share the day-to-day experience of living with PwD may be critical and unsympathetic, and emotional reactions such as anger, helplessness and guilt increase the caregiver burden.

Most evidence for dementia caregiving focuses on negative impacts on caregivers (Kolanowski *et al.*, 2018). However, positive outcomes such as sharing love and joy

(Todorova *et al.*, 2016; Mace and Rabins, 2017), meaningfulness (Shim *et al.*, 2013; Jennings *et al.*, 2016) and satisfaction of engagement in care are also reported.

2.3 Theoretical and conceptual base for dementia caregiving

Most of the current literature on caregiving is built upon stress and coping models and stress process models which are described below (Diwan, Hougham and Sachs, 2004; Hilgeman *et al.*, 2009; Judge, Menne and Whitlatch, 2009). Pearlin *et al.*, (1990) proposed a stress process model for dementia caregivers that explains the link between personal, social and economic characteristics of the caregiver (e.g. life events, psychological strain, family and social network, caregiving role), characteristics of the PwD (e.g. severity of BPSD), caregiving history (e.g. relationship between the PwD and caregiver, duration of caregiving) and the caregiver strain. This model describes a process with several interrelated domains: background and context, primary stressors (e.g. cognitive status of the PwD, behavioural problems) or secondary stressors (e.g. job or family conflict, constriction of social life), mediators of stress (e.g. coping and social support) which create variability in the caring experience; and the outcomes of caregiver stress (e.g. depression, anxiety, physical health, yielding of caregiver responsibilities to others).

Other research has revealed the multidimensional nature of caregiving in addition to caregiver stress and burden. A later study by Hilgeman *et al.* (2009) to test Pearlin's caregiver stress process model reports that caregivers' race or ethnicity moderates the perceived burden of care; for example, White or Caucasian caregivers experienced more intrapsychic strain (i.e., ability to maintain a sense of personal identity as a caregiver; measured by confidence in caregiving, caregiving skills, rewards or positive

aspects associated with caregiving and higher values) than Black, African American, Hispanic or Latino caregivers. It is also documented that caregiving processes and outcomes are influenced by the demographic changes in the families; for example, increase in blended and other non-traditional families (e.g. nuclear families) and divergent cultural views among family members towards definitions and meanings of dementia and caregiving (Klein, 2014).

In response to different causes of burden and distress among distinct populations of caregivers new models and theories have emerged for understanding dementia caregiving. For example, Sethabouppha and Kane (2005) proposed a caregiving model influenced by Buddhism for people with serious mental illnesses. The model describes caregiving as reflected in the Buddhist practices of compassion, and, the management and acceptance of suffering. Montgomery and Kosloski (2009) proposed caregiver identity theory which explains caregiving as a 'career'. This theory acknowledges caregiving as a journey that includes a 'series of transitions' that result from changes in the context of caregiving and in personal norms and values that are grounded in family, society and culture (Kwak *et al.*, 2011). The transition from a family member, relative or friend (non-caregiver) to an informal caregiver and experiencing specific patterns of caregiving outcomes (e.g. work overload, burden, depression) often mark the beginning of the 'caregiving career' (Nikzad-terhune, 2011). This phenomenon is defined as 'identity discrepancy' (Kwak *et al.*, 2011). The caregiver identity theory highlights that the caregiver role is dynamic; emerging from an existing role relationship; every caregiving situation is unique and there are differences among caregivers in the way they perceive the caregiving role (due to ethnic and cultural influences), expectations concerning duties, and circumstances that allow them to

ultimately relinquish the roles (Montgomery and Kosloski, 2009). According to this theory, an original family relationship (e.g. mother-daughter) can be transformed into a new relationship characterised by caregiving, and this change in identity has long term implications for the caregiver (e.g. lifestyle changes, bereavement, role acceptance or experience of burden) (Schulz and Martire, 2004; Kwak *et al.*, 2011; Peacock *et al.*, 2018).

2.4 Socio-cultural and economic variations in caregiving practice

Chapter One, Section 1.5 detailed the cultural and social differences in dementia care. This section provides further information on socio- cultural and economic diversity in dementia caregiving. Evidence shows that the ethnic, religious and socio-cultural backgrounds of the caregivers shape their illness perceptions and care practices.

Variations in Illness perception

Caregivers can conceptualise and experience their caregiving journey differently. For example, illness perception and identification of causes of dementia (La Fontaine *et al.*, 2007; Schoonover *et al.*, 2014), views towards the caregiver role (Sethabouppha and Kane, 2005; Shim *et al.*, 2011), how the family members coped and reacted to the course of dementia from the onset of illness (Connell and Gibson, 1997; Sayegh and Knight, 2013; Schoonover *et al.*, 2014) and involvement and level of commitment to care (Brodaty, Green and Koschera, 2003; Chan, 2011; Wang, 2012, 2014) were largely influenced by the socio-cultural background of the informal caregivers (e.g. cultural values and religious teaching towards caregiving). Systematic reviews report evidence of greater stigma among ethnic minority groups and evidence that they were less likely to recognise BPSD as an illness than White individuals, and more likely to ascribe these

characteristics to the normal ageing process or give cultural or religious explanations to BPSD (Bunn *et al.*, 2012; Hossain *et al.*, 2018).

Variations in Caregiving

In many Asian countries, older adults are accorded great respect, both within the families and in society (Gupta and Pillai, 2002; Kalaria *et al.*, 2008; Shaji, 2009; Wang *et al.*, 2014; Ali and Bokharey, 2015; Jutlla, 2015b). Family is a strong institution in most Asian countries, and therefore, it is expected that families care for the elderly at home (Shaji, 2009; Qadir *et al.*, 2013; Abeywickrema, Weerasundera and Ranasinghe, 2015; Ali and Bokharey, 2015; Islam *et al.*, 2018). In most situations, elderly people live with their children or siblings, and therefore, caregiving is viewed as a duty or responsibility of the children or other family members (Dilworth-Anderson and Gibson, 2002; Shaji, 2009; Chang, 2010; Patel and Shaji, 2010; Chan, 2011; Chen *et al.*, 2014). In some contexts, socio-cultural values and norms favour home-based care when compared to institutionalised care for PwD (Pattanayak *et al.*, 2010; Wang *et al.*, 2014; Hossain *et al.*, 2018; Lee *et al.*, 2019). In some countries such as China, Nepal, India, Sri Lanka and Vietnam, caring for older people is assigned to family members by law as a mandatory requirement (Wang *et al.*, 2014; UNFPA Report, 2017). In Malaysia and Thailand placing PwD in care homes was perceived as abandonment and against religious obligations (Sethabouppha and Kane, 2005; Nikmat, Hawthorne and Al-Mashoor, 2011).

Variations in accessing dementia services

Information about dementia management and caregiving is insufficient in most LAMIC (Shaji, 2009; Maestre, 2012; Ferri and Jacob, 2017). However, the evidence shows that the bio-medical model is widely practiced, but may not be the best practice in most

LAMIC, when considering the socio- cultural and economic differences within each setting. For example, In Pakistan caregivers have negative attitudes towards help seeking for dementia (Willis *et al.*, 2020), in China many people prefer Chinese medicines for dementia management (Jia *et al.*, 2019) and in India many caregivers believe in traditional healing (Pattanayak *et al.*, 2010; Schoonover *et al.*, 2014) and therefore, do not use the bio-medical model. A large number of PwD remain undiagnosed in LAMIC due to lack of awareness, stigma, and the cultural influence of home-based caregiving for elderly by the close family members despite the severity of dementia (Ali and Bokharey, 2015; Ferri and Jacob, 2017). Therefore, it is necessary to evaluate the usefulness and applicability of these dementia care models in Asian, LAMIC settings.

Studies on migrated ethnic minority groups living in HIC show that family caregivers show less interest in using the medical model due to their socio- cultural beliefs and attitudes towards dementia management (Jutlla, 2013b, 2015b; Jennings *et al.*, 2016; Hossain *et al.*, 2018; Stephan *et al.*, 2018). For example, a group of Sikh caregivers in the UK were reluctant to seek medical treatments or professional support and did not use community or social care services for dementia due to their migration identities and cultural perspectives on caregiving (Jutlla, 2015a, 2015b). Lack of dementia awareness, language barriers, and socio- culturally driven attitudes such as shame and stigma towards dementia were also reported as significant reasons for not using available services for dementia such as community services or care facilities in nursing homes among Asian families living in the UK (Jutlla, 2013b, 2015b; Hossain *et al.*, 2018). In contrast, the lack of formal and institutional care for dementia in LAMIC places a huge burden on informal caregivers (Ferri and Jacob, 2017).

When compared to LAMIC, dementia awareness, early diagnosis and community-based management of dementia are more advanced in HIC (Banerjee, 2013; Alzheimer's Association, 2015; Blakemore *et al.*, 2018; Hossain *et al.*, 2018). In LAMIC, the overwhelming majority of PwD live in their homes, and caregiving is provided by informal caregivers, outside of residential care or specialised dementia care facilities (World Alzheimer Report 2013; Zwaanswijk *et al.*, 2013; Orpin *et al.*, 2014; Chiao, Wu and Hsiao, 2015; Vaingankar *et al.*, 2016; Mace and Rabins, 2017). A recent survey among eight European countries (n=1223) shows that approximately half of PwD (49%) receive home-based care and 40% attended community-based daycare services in Europe (Sutcliffe *et al.*, 2017). Furthermore, community care services in HIC provide support and facilities such as assistance in home-based care, day care, respite care or psychological support services to informal caregivers (Kwak *et al.*, 2011; Johnson *et al.*, 2013; Mace and Rabins, 2017). However, studies also report that despite the availability of support and community services, PwD and informal dementia caregivers use fewer services when compared to others who need care (e.g. disabled people) (Weber, Pirraglia and Kunik, 2011; Phillipson, Jones and Magee, 2014; Bieber *et al.*, 2017; Stephan *et al.*, 2018). Caregivers and PwD from ethnic minority groups could have enhanced access to support services, if they would recognise dementia as an illness, have knowledge about it and have information and guidance on how to access those services (Cooper *et al.*, 2010; Xiao, Habel and De Bellis, 2015; Hossain *et al.*, 2018; Stephan *et al.*, 2018; Bieber *et al.*, 2019).

Variations in experience of caregiver burden

The burden of care experienced by the informal caregivers in LAMIC is associated with different factors compared to the burden experienced by caregivers in HIC (Jutlla,

2013b; Mace and Rabins, 2017; Blakemore *et al.*, 2018). In LAMIC, there is a scarcity of economic, social and professional resources and community services for PwD and their caregivers (Prince *et al.*, 2011, 2015; Ferri and Jacob, 2017). Barriers to health care access, diagnosis and care, limited expertise among mental health professionals and caregiver burden are also commonly reported as challenges of dementia caregiving in LAMIC (Zarit, 2011; Maestre, 2012; Wang *et al.*, 2014; Xiao, Habel and De Bellis, 2015; Thirthalli *et al.*, 2016).

However, informal caregiving for PwD has been associated with high levels of burden, stress and depression in both HIC and LAMIC (Campbell *et al.*, 2008; Prince *et al.*, 2009; Shaji, 2009; Meyer, Cullough and Berggren, 2016; Bieber *et al.*, 2017). Evidence shows that the levels of caregiver burden experienced by caregivers in LAMIC are as high as in HIC despite extended family support received by the former (Shaji, 2009; Ali and Bokharey, 2015). The dependency of PwD, BPSD of PwD, poverty of the families, socio-demographic transitions and lack of support are all strongly linked to caregiver stress (Shaji *et al.*, 2002; Pattanayak *et al.*, 2010; Chan, 2011).

As a result of recent social and demographic transitions in LAMIC, and trends in changing traditional family functions, the lives of PwD may be affected. For example, there is a trend among families in most LAMIC to have fewer children than previous generations, people are less likely to get married and the children are more likely to separate from the parents due to education, work commitments or migration (Patel and Shaji, 2010; Xiao, Habel and De Bellis, 2015). With declining family support, there is an increased need for improving community and primary care services to ensure the care and well-being of PwD and caregivers (WHO, 2018b). Chapter One, Section 1.7.4

(pages 31 – 33) discussed the impact of demographic, social and economic transition on family caregiving in Sri Lanka.

Variations in policies and standards of dementia care

The evidence base for dementia care predominantly comes from HIC (Prince *et al.*, 2009). Similarly, the majority of formal care models for dementia, policies and strategies, care guidelines and interventions for dementia management recommended are mostly based on westernised, HIC settings (Chang *et al.*, 2009; Prince *et al.*, 2009; Kinnaird, 2010; Monaghan, 2013; Jutlla, 2015b). As aforementioned, LAMIC have very limited dementia services, most countries do not have comprehensive health and social care systems or support systems for looking after older adults in general (Prince *et al.*, 2009). Ferri and Jacob (2017) state that dementia is 'under-recognised, under-disclosed, undertreated, and undermanaged' in most LAMIC. In South Asia, dementia services are largely restricted to tertiary care hospitals where the dementia population is high (Shaji, 2009; Shaji, Jotheeswaran and Girish, 2010; Jia *et al.*, 2016). Comparatively in HIC, there is particular interest in promoting person-centred interventions, operating the case management, long-term care pathways and improving dementia care at the level of primary care (Prince, Comas-Herrera, *et al.*, 2016); perhaps because primary health care systems are well developed in those countries (Robinson *et al.*, 2010). Services also include interventions and programmes for caregivers and PwD to address their concerns and support needs (Brodaty, Green and Koschera, 2003; Ducharme *et al.*, 2011; Beinart *et al.*, 2012; Lopez-Hartmann *et al.*, 2012; Whitebird *et al.*, 2013; Ducharme *et al.*, 2014).

Both the WHO and Alzheimer's Disease International (ADI) have called on national governments to make dementia a priority community health concern. The ADI report

that countries in the Asia-Pacific region need an integrated and coordinated care pathways to address the burden of dementia despite the limitations of resources (ADI, 2014). Countries such as Australia, South Korea, Japan, and Taiwan report that their governments have formal national dementia strategies; some countries have initiated measures to improve dementia awareness, diagnosis, and care for PwD, but no formal government involvement in many of the countries in this region (ADI, 2014). Considering the different population growth rates, financial, and social aspects globally, the WHO recommends that all countries develop their own national strategies in order to prepare for the growing burden of dementia and also to ensure financial security, health and wellbeing of older people (ADI, 2015a; WHO, 2018b; WHO, 2018c). These strategic frameworks would also highlight the importance of enhancing equitable access to services and planning dementia care based on each country's distinct political, cultural and socio-economic context (WHO, 2018c).

The WHO dementia global plan from 2018 encourages research on health or psycho-social aspects of PwD and their family caregivers (WHO, 2018c). Research priorities include; research into screening and detection of dementia, treatments for dementia, enhancing access to health care, raising awareness, reducing stigma and social isolation as well as measures to improve quality of life of PwD and their caregivers (WHO, 2015).

2.5 Chapter summary

The focus of this chapter was to review conceptual and empirical literature on dementia care, care models, and aspects of informal caregiving. The role of the informal caregivers and the impact of dementia on PwD and caregivers were explained against a backdrop of social and cultural context regarding dementia caregiving drawing on research carried in different settings. This chapter also reviewed the similarities and differences in dementia care between HIC and LAMIC, providing an exploration of the critical background issues that may impact on informal caregiving in the study context. The evidence of different caregiving perspectives, theories and models emanating from existing literature will also be relevant and support the interpretations and the claims of this thesis.

Existing literature revealed that most PwD in LAMIC are cared for by their family caregivers without much support from formal health care systems. Socio-cultural differences, economic and resource limitations in many LAMIC appeared to be less considered when replicating the dementia management programmes of HIC in LAMIC. Less qualitative research has been carried out in South Asian regions in particular on experience of dementia caregivers. Having explored the literature on dementia caregiving more broadly, the next chapter will focus specifically on the Sri Lankan context, reporting the findings of a systematic review of dementia research activity in Sri Lanka.

Chapter 03

Systematic review on dementia research activity in Sri Lanka

Chapter Two reviewed existing literature on dementia care and informal caregiving. This chapter describes the methodology and the key findings of a systematic mapping review on dementia research activity specifically focused on Sri Lanka to complement the overall literature review of the thesis.

3.1 Introduction

Previously, many systematic reviews on dementia have been carried out in all the aspects including prevalence, awareness, dementia management, patient and caregiver characteristics, effectiveness of interventions, the factors associated with caregiver burden and the challenges of dementia care (Peacock and Forbes, 2003; Etters, Goodall and Harrison, 2008; Prince *et al.*, 2013; Chiao, Wu and Hsiao, 2015; Blakemore *et al.*, 2018; Hossain *et al.*, 2018). However, to-date no systematic reviews have been carried out to explore existing evidence of dementia research reported from Sri Lanka. The purpose of this systematic review was to understand the current research focus on dementia in Sri Lanka, identify research gaps related to caregivers of those with dementia and to facilitate the development of novel research questions.

3.2 Aim and Objectives of the systematic review

This systematic review aimed to explore the breadth of dementia research activity in Sri Lanka. The approach used was therefore a wide search to capture all aspects of dementia research conducted in Sri Lanka (e.g. dementia prevalence, pathophysiology,

screening for dementia, validation of screening tools for dementia, management of care, care models or services, and the studies about PwD and caregiver characteristics) and then map out and categorise existing literature identifying the research gaps (Grant and Booth, 2009).

The following were the specific objectives developed in order to achieve the aim of this review:

1. To review evidence of dementia research activity in Sri Lanka
2. To map the output of dementia research activity to assess the current research focus and priorities in Sri Lanka
3. To describe the measures of dementia care management and services within the Sri Lankan context

3.3 Materials and Methods

This section describes the data sources, search strategy and search terms, inclusion and exclusion criteria, and the quality appraisal methods that were used for selection of the studies for this systematic mapping review. The data extraction procedure is discussed with tables to summarise the details of the studies that are utilised for the review.

3.3.1 Protocol

The protocol for the systematic review was developed based on the Population, Intervention, Comparison, Outcomes of interest, Setting and study design (PICOS) format with support and guidance received from the systematic review team at the School of Primary, Community and Social Care at Keele University. The search strategy was developed and approved by experts from the systematic review team. The

protocol and search strategy were registered in Prospero International prospective register of systematic reviews (Reg No: CRD42017052071).

3.3.2 Identification of studies

The search was carried out by using NHS openAthens interface, the Cochrane Central Register of Systematic Reviews and Controlled Trials. The databases searched were: Medline, CINAHL, PsycINFO, EMBASE and AMED. In order to obtain relevant locally published articles within the context of Sri Lanka, Journals Online (SLJOL), a database for online published journals in Sri Lanka (www.sljol.info/) was accessed. A grey literature search was also carried out manually (to look for unpublished data from Sri Lankan studies) from the Post Graduate Institute of Medicine (PGIM) library, Sri Lanka. During the grey literature search the submitted theses and dissertations for PhD, MD and MSc were searched up to the last search date. Initial searches were carried out between 28th September and 10th October 2016. A top-up search was carried out on 3rd April 2019.

3.3.3 Search strategy and Search terms

The search terms were developed and discussed with the supervisory team and agreed in consultation with the systematic review committee. For each database a combination of specific keywords consisted of search terms; for example, (dement* OR neurocognitive disorder* OR alzheimer* OR "lewy bod*" OR "vascular cognitive impair*" OR "cognitive impairment") AND ("Sri Lanka*" OR Colombo OR Ceylon). The complete search strategy for the review is described in Table 3.1. Next, the search was conducted for locally (Sri Lanka) published articles and grey literature at SLJOL covering the full range of online research journals available in Sri Lanka. An online search of Sri Lankan university and government websites was also carried out in order

to identify further articles, reports, editorials or resource texts. PhD theses, MD and MSc dissertations submitted to PGIM were also searched manually using the library catalogue to find any related information in the unpublished dementia studies. Records of on-going research, conference proceedings and theses were also hand searched for unpublished research findings. Reference lists of included papers and relevant reviews were searched by hand, and authors of included papers were contacted where possible, to request full papers which were not available online and to ask if they knew of other relevant studies.

Table 3.1: Search Strategy

Database	**Search Strategy**
Medline	S1 exp DEMENTIA/ S2 exp NEUROCOGNITIVE DISORDERS/ S3 dement*.ti,ab S4 alzheimer*.ti,ab S5 “lewy bod*”. ti,ab S6 “vascular cognitive impair*”.ti,ab S7 “vascular dementia”.ti,ab S8 “neurocognitive disorder*”.ti,ab S9 S1 OR S2 OR S3 OR S4 OR S5 OR S6 OR S7 OR S8 S10 exp SRI LANKA/ S11 “sri lanka*”.af S12 colombo.af S13 ceylon.af S14 S10 OR S11 OR S12 OR S13 **S15 S9 AND S14**
CINAHL	S1 exp DEMENTIA/ S2 dement*.ti,ab S3 alzheimer*.ti,ab S4 “lewy bod*”.ti,ab S5 “vascular dementia”.ti,ab S6 “vascular cognitive impair*”.ti,ab S7 S1 OR S2 OR S3 OR S4 OR S5 OR S6 S8 exp SRI LANKA/ S9 “sri lanka*”.af S10 colombo.af S11 ceylon.af S12 S8 OR S9 OR S10 OR S11 **S13 S7 AND S12**

Table 3.1: Search Strategy *(Cont.)*

Database	Search Strategy
PsycINFO	S1 exp DEMENTIA/ S2 exp COGNITIVE IMPAIRMENT/ S3 exp "ALZHEIMER'S DISEASE"/ S4 "cognitive impairment".ti,ab S5 dement*.ti,ab S6 alzheimer*.ti,ab S7 "lewy bod*". ti,ab S8 "vascular cognitive impair*".ti,ab S9 "vascular dementia".ti,ab S10 S1 OR S2 OR S3 OR S4 OR S5 OR S6 OR S7 OR S8 OR S9 S11 "sri lanka*".af S12 colombo.af S13 ceylon.af S14 S11 OR S12 OR S13 **S15 S10 AND S14**
EMBASE	S1 exp DEMENTIA/ S2 dement*.ti,ab S3 alzheimer*.ti,ab S4 "lewy bod*". ti,ab S5 "vascular cognitive impair*".ti,ab S6 "vascular dementia".ti,ab S7 S1 OR S2 OR S3 OR S4 OR S5 OR S6 S8 exp SRI LANKA/ S9 "sri lanka*".af S10 colombo.af S11 ceylon.af S12 S8 OR S9 OR S10 OR S11 **S13 S7 AND S12**
AMED	S1 exp DEMENTIA/ S2 dement*.ti,ab S3 alzheimer*.ti,ab S4 "alzheimer* disease".ti,ab S5 "lewy bod*". ti,ab S6 "vascular cognitive impair*".ti,ab S7 S1 OR S2 OR S3 OR S4 OR S5 OR S6 S8 "sri lanka*".af S9 colombo.af S10 ceylon.af S11 S8 OR S9 OR S10 **S12 S7 AND S11**

Table 3.1: Search Strategy *(Cont.)*

Database	Search Strategy
PUBMED	S1 dementia.ti,ab S2 alzheimer*.ti,ab S3 "alzheimer* disease".ti,ab S4 "lewy bod*". ti,ab S5 "vascular cognitive impair*".ti,ab S6 "vascular dementia".ti,ab S7 "neurocognitive disorder*".ti,ab S8 S1 OR S2 OR S3 OR S4 OR S5 OR S6 OR S7 S9 "sri lanka*".af S10 colombo.af S11 ceylon.af S12 S9 OR S10 OR S11 **S13 S8 AND S12**
Cochrane Central Register of Systematic Reviews and Controlled Trials	S1 exp DEMENTIA/ S2 Dement* S3 Alzheimer* S4 "vascular cognitive impair*" S5 "lewy bod*" S6 S1 OR S2 OR S3 OR S4 OR S5 S7 SRI LANKA/ S8 "sri lanka*" S9 colombo S10 ceylon S11 S7 OR S8 OR S9 OR S10 **S12 S6 AND S11**
SLJOL (Sri Lanka Journals Online)	Ceylon Medical Journal (CMJ) Sri Lanka Journal of Psychiatry (SLJP) Journal of the Ceylon College of Physicians (JCCP)
Grey Literature	Reference lists, and Hand searched in SL journals, conference proceedings and MD/ PhD theses in PGIM library/University and government websites in Sri Lanka

3.3.4 Inclusion criteria

The review included all the papers published at present regardless of study design. Hand searched papers from Sri Lankan journals, conference proceedings, opinion papers for journals, oration papers and unpublished dissertations or theses were also included as grey literature. This enabled me to review all of the related studies to-date. The following criteria based on PICOS format was used when including the studies:

Population, or participants and conditions of interest

- All types of research studies conducted in Sri Lanka were included if they had a focus on dementia. Any type of study that reported information on dementia and Sri Lanka were considered as potentially eligible for the review; including cohort studies, cross-sectional studies, case reports, case studies, prevalence studies, instrument validation studies, clinical trials, and case-control studies among the selected papers. Conference abstracts and opinion pieces were also included. The grey literature on unpublished studies was also included if they presented as journal or book reviews, PhD or MD theses that are relevant to review objectives.
- The participants included older adults, people with dementia (PwD), formal or informal caregivers who are involved in care provision for PwD.
- The review strategy considered all the possible articles related to older adults (age > 60) (WHO, 2010; Satharasinghe, 2016), dementia, Alzheimer's disease or other types of dementia, cognitive impairment, management of dementia and caregiving for dementia in the Sri Lankan context.
- Articles meeting the inclusion criteria were considered regardless of the publication status and the date of publication.

Interventions or exposures

At the beginning of the search a combination of the following groups of search terms were used in order to retrieve the largest possible number of articles (see Table 3.1, page 64-66):

- Dementia/ Alzheimer's disease/ Lewy bodies dementia/ Vascular dementia/ fronto-temporal dementia
- Neurocognitive disorders/ Cognitive impairment
- Sri Lanka/ Ceylon/ Colombo

Outcomes of interest

Whilst the review aimed to capture all studies on dementia in Sri Lanka, aligned to the focus of this thesis, the primary outcome of interest was issues related to caregiving within Sri Lanka; including, aspects of care (both formal and informal), the definitions of caregivers for those with dementia, and how the caregiving role is described within the Sri Lankan context, caregiver characteristics such as burden, stress and associated factors, physical and mental health among the caregivers, and issues or challenges related to dementia care. Other aspects related to caregiving and dementia, in general, were also considered as secondary outcomes:

- evidence on care models, treatment approaches for dementia
- the course of the disease
- prevalence of dementia
- the screening instruments and treatment methods used within the Sri Lankan context

3.3.5 Exclusion criteria

The exclusion criteria included articles on any other memory problem rather than dementia (for example delirium, memory loss due to traumatic events or amnesia). Due to the focus on older adults, articles were excluded if the studies were on HIV related dementia and acquired immunodeficiency syndrome dementia complex if they were not focused on older adults.

3.3.6 Study selection

Searches were carried out as outlined in the Section 3.3.3 above and the number of references from each database were recorded and references were imported into the reference management database, Refworks. Inclusion of papers involved several stages as suggested by Boland, Cherry and Dickson (2014). The first step of title, abstract and full-text screening was to remove duplicates. The 'Exact Match' (i.e., the similar records with the same title, abstract and full-text included in different databases) and then 'Close Match' articles (i.e., same record with minor differences in how a reference is indexed in different databases) on the search results were removed at first. After that, the lists of references were reviewed in order to find additional relevant articles. Once the duplicates were removed, the selection of records started with the screening of the titles and abstracts. Articles were rejected if they showed no relation to the inclusion criteria based on the title and abstract. Porritt *et al.* (2014) recommend two reviewers select articles in order to ensure transparency and reproducibility of the study selection process. Accordingly, the first round of searches was conducted independently by two reviewers Kalpani Abhayasinghe (KA) and Athula Sumathipala (AS). Both agreed on the inclusion of articles if the following

information was provided in the title or abstract. In cases where it was unclear from the title or abstract whether a paper was relevant, the full texts were also screened.

3.3.7 Quality appraisal of the selected studies

Risk of bias assessment for each included study is recommended in systematic reviews in order to evaluate rigour and relevancy of the records and to establish transparency of the review results (Boland, Cherry and Dickson, 2014). KA and Lasith Dissanayaka (LD) assessed full-text papers and performed the critical appraisal for both quantitative and qualitative evidence using a quality assessment tool (based on Joanna Briggs Institute (JBI) critical appraisal tools - http://joannabriggs.org/research/critical-appraisal-tools.html) to rate the sources of potential bias in each study. JBI critical appraisal tools are a set of checklists (thirteen) or standardised assessment tools for quantitative and qualitative studies. The JBI critical appraisal tools were chosen as they cover the full range of study designs included in the current review (for example; qualitative studies, case reports, case studies, cohort studies, diagnose test accuracy, mixed-method studies, validation studies, text and opinion papers). Quality assessment was carried out independently by KA and LD; sub-samples were cross-checked with AS for consistency and any disagreement about the papers was resolved.

Evidence in the records was rated considering the study purpose, study design, sample size, response rate, method of data analysis, the validity of the results and reporting of the findings. A scale (of 0-10) was used to rate the strength of conclusions drawn from each study. Consequently, review items were judged and rated to be of high quality (total score 7-10), moderate quality (total score 4-6), or low quality (total score 0-3). However, the quality assessment was not used to exclude the articles. The articles that

met the inclusion criteria and contained information regarding dementia research activity in Sri Lanka were included in the review rather than excluding them based on their quality. The quality ratings were used to develop a greater understanding of the records and their results, and as a measure of credibility of the findings presented (Boland, Cherry and Dickson, 2014). The number of articles remaining after each stage was recorded. This process is illustrated in Figure 3.1: PRISMA criteria for article selection (page 74).

3.3.8 Data extraction

The data extraction was performed by KA, and each one of the papers was cross-checked by the second reviewer (LD). AS helped to resolve any disagreements. No paper was excluded incorrectly, thereby confirming the satisfactory reliability of our extraction process. Data extracted included the following information (See Appendix 02 for the data extraction form).

- General information - (Date of data extraction, Record number article title, authors, year of publication)
- Aim and objectives of the study
- Methodological characteristics of the study (such as study design, study setting, study inclusion/exclusion criteria, recruitment procedures used, sample size, response rate), type of analyses methods used (for example qualitative, quantitative, mixed-methods or case study),
- Data collection tools used in the study,

- Descriptors of the intervention (when the papers are based on intervention studies, that is, whether the intervention was with the person with dementia (PwD), with family carers or with staff)
- Dementia severity and diagnostic details (dementia type, information about non-responders, demographic information including incidence rate and prevalence rate of dementia)
- Caregiver burden measures, risk factors for caregiver burden (PwD characteristics, Caregiver characteristics)
- Details of relevant outcome measures and summary outcome data (results, conclusions, recommendations, limitations of the study and personal notes and remarks (e.g. limitations of the study)

3.4 Analysis and Narrative synthesis

Aligned to the aims of the review, a descriptive narrative analysis was carried out. In addition, the included records showed a greater heterogeneity of the study designs, sample sizes, study aims, interventions and reported outcomes. Therefore, the meta-analysis approach would not be considered. The initial step of the narrative analysis was to cluster and map the articles into domains. Each study was assigned to one or more domains namely: Prevalence, Pathophysiology, Screening for dementia (e.g. instrument validation and screening process), Management of dementia (e.g. treatment, caregiving and care models). Studies were classified according to their domains; narrative synthesis allowed the identification of study types, patterns of data and research gaps by comparison within and across the studies. Mapped articles were tabulated based on their domain and compared within and across studies. The

systematic 'narrative synthesis' approach used allowed the identification of patterns across the data reported in the reviewed articles to draw informative conclusions relevant to the review objectives (Popay *et al.*, 2006).

3.5 Results

3.5.1 An overview of the general results: Selection of papers

Based on the initial searches, 971 articles were retrieved (up to April 2019). Among these, 449 duplicates were removed. Out of the remaining 522 articles, 474 were excluded based on title and abstract screening, as they did not match the screening criteria (See Figure 3.1, page 74). Forty-eight records were eligible for full-text screening; among them, 20 were excluded for the following reasons: irrelevant titles and abstracts (not related to older adults, dementia studies in Sri Lanka), full paper not available, or insufficient data. As aforementioned, none of the articles were excluded based on quality assessment criteria. Twenty-eight records were included in the narrative synthesis. Among the selected records there were 20 journal articles (full papers), three opinion papers for journals, three conference abstracts and two MD theses. Where appropriate, we contacted the study authors for further information; three articles which were not available online were received from the authors upon request. Table 3.2 (page 76) illustrates a summary of included records.

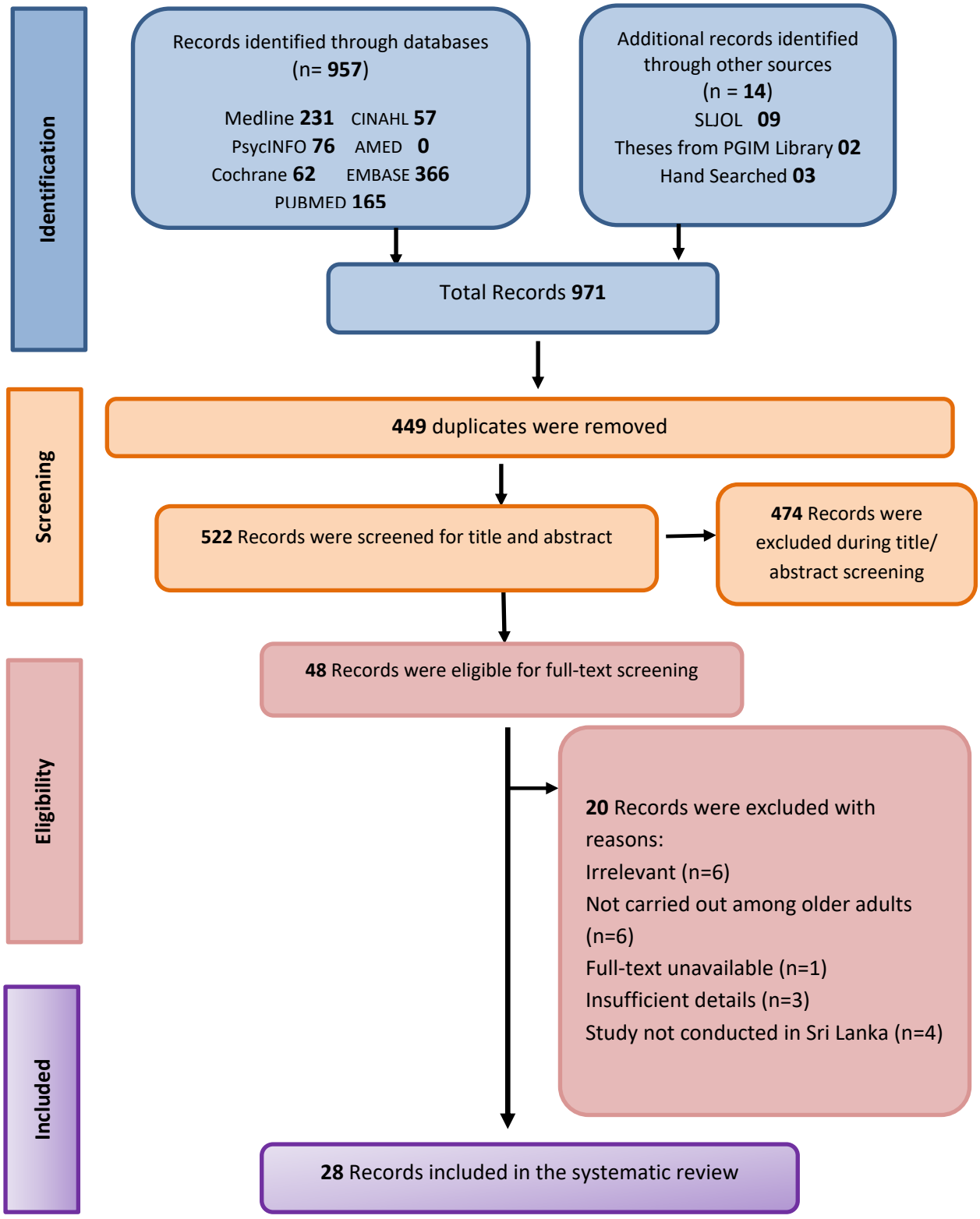

Figure 3.1: PRISMA criteria for article selection

3.5.2 Mapping the dementia research conducted in Sri Lanka

Research activities reported in the included records represented evidence across four key domains. Some papers reported information on more than one domain. Figure 3.2 illustrates the number of articles categorised within each domain. Table 3.2 lists the summary of included articles, papers and grey literature included in the review.

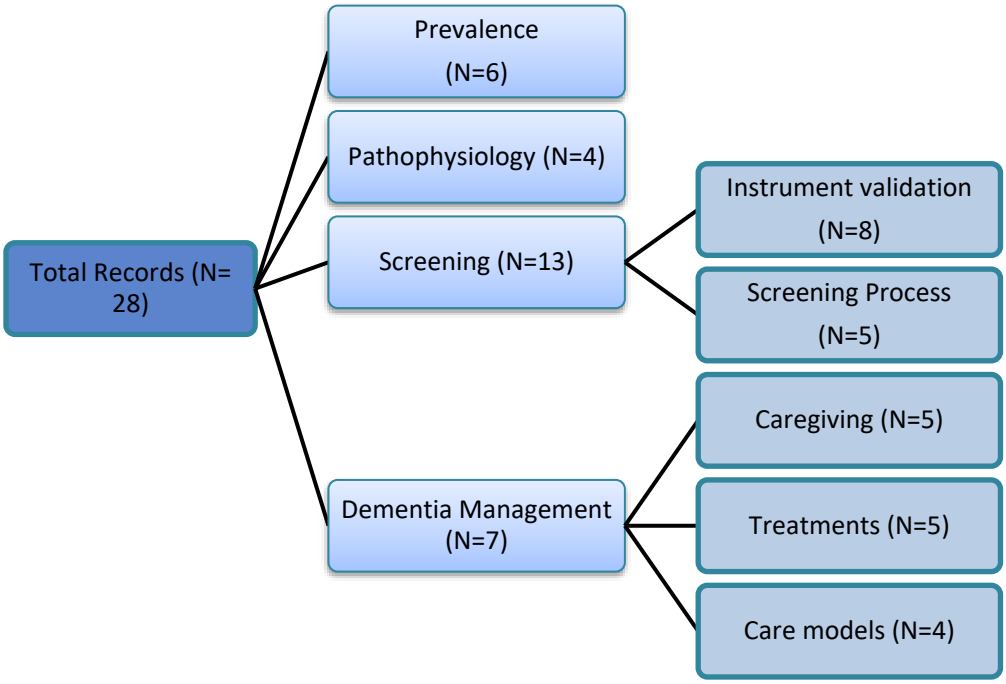

Figure 3.2: Map of domains and sub-domains

Table 3.2: The summary of included studies and papers.

S No	Title	Source	Authors	Aim of the Study/ paper	Publication Type	Mapping Category/ Domain	Quality Assessment
1	Prevalence of Dementia in a semi-urban population in Sri Lanka: report from a regional Survey	Int j Geriatric Psychiatry; 2003; 18: 711 – 715	de Silva, HA; Gunatilake, SB; Smith, AD	To determine the prevalence of AD and other dementias in a semi-urban elderly Sinhala speaking population	Journal: Article	Prevalence	Moderate
2	Assessment of the level of care-burden in informal caregivers of patients with dementia	SL j Psychiatry 2015; 6(1): 4 – 8	Abeywickrema, S; Weerasundera, R; Ranasinghe, K	1. To describe the level of care-burden in cares of patients with dementia 2. To explore possible associations between care-burden and other variables such as socio-demographic factors and psychiatric morbidity	Journal: Article	Caregiving aspects (Carer Burden)	High
3	Dementia care: Issues and challenges in a developing Asian country	Asian Journal of Psychiatry; 2011; 4(S18_01)	Williams, S	To describe the issues and challenges of current dementia care services in Sri Lanka	Conference Abstract	Management of Dementia (Issues and challenges of dementia care)	Low
4	Sharing skills in dementia care with staff overseas	Nursing Older people; 2014; 26(4): 35 -39	Marcal- Grilo, J	To share the author's experience in volunteering in a mental health care setting in Sri Lanka	Journal: Article	Management of Dementia and Caregiving (Care skills among nurses)	moderate

Table 3.2: The summary of included studies and papers (*Cont.*)

S No	Title	Source	Authors	Aim of the Study/ paper	Publication Type	Mapping Category/ Domain	Quality Assessment
5	Efficacy of rivastigmine on activities of daily living in Sri Lankan patients with Alzheimer disease and on improving caregiver burden: a prospective study	The Ceylon medical journal; 2005; 50(3): 106-109	de Silva HA; Pathmeswaran A; Gunatilake SB	To investigate the efficacy of Rivastigmine treatment on activities of daily living in patients with mild to moderate AD and possible benefits of this therapy on caregiver stress levels	Journal: Article Prospective cohort Study	Management of Dementia (Treatment) And Caregiving (Carer Burden)	High
6	Alzheimer's disease—time to act is now	The Ceylon medical journal; 2005; 50(1): 1-4	de Silva, HA	To highlight the timely need of starting a national programme to tackle dementia in Sri Lanka	Journal: Article Opinion paper	Management of Dementia	Low
7	Medial temporal lobe atrophy, apolipoprotein genotype, and plasma homocysteine in Sri Lankan patients with Alzheimer's disease	Experimental Ageing Research; 2005; 31(3): 345-354	de Silva HA; Gunatilake SB; Johnston C; *et al.*	To study the association of AD with the total plasma homocysteine and apolipoprotein E genotype To study the usefulness of measuring medial temporal lobe thickness for the diagnosis of AD	Journal: Article Case-control study	Pathophysiology Screening	Moderate
8	Cytoskeletal pathologies of age-related diseases between elderly Sri Lankan (Colombo) and Indian (Bangalore) brain samples	Current Alzheimer Research; Mar 2016; 13(3): 268-280	Wijesinghe, P; De Silva, KRD; Shankar, SK; *et al.*	To compare ageing cytoskeletal pathologies between in India and Sri Lanka using autopsy brain samples of elderly	Journal: Article	pathophysiology	Moderate

Table 3.2: The summary of included studies and papers (*Cont.*)

S No	Title	Source	Authors	Aim of the Study/ paper	Publication Type	Mapping Category/ Domain	Quality Assessment
9	Vascular risk factors in manifestation of Alzheimer's disease related neuropathological changes: First autopsy and genetic evidence from a South Asian ageing population	Journal of Cerebral Blood Flow and Metabolism 2017; 37(1S): 196 -197	Wijesinghe, P; Shankar, SK; Yasha, TC; De Silva, KRD	To investigate vascular risk factors associated with determining the aetiology of sporadic AD	Conference proceedings: Abstract (Poster viewing session II-(PS02-045)	pathophysiology	Moderate
10	Mini Mental State Examination in Sinhalese: A sensitive test to screen for dementia in Sri Lanka	International Journal of Geriatric Psychiatry; 2002; 17(2): 134-139	de Silva, HA; Gunatilake, SB	To develop and validate a Sinhala translation of the MMSE	Journal: Article	Prevalence and Screening (Instrument validation)	High
11	Norms for the mini-mental state examination from an elderly Sri Lankan sample. .	Int J Geriatr Psychiatry 2009, 24:666-670	De Silva, R; Disanayaka, S; De Zoysa N; *et al.*	To derive norms for the Mini Mental State Examination (MMSE) based on age, gender and level of formal education among the elderly in Sri Lanka	Journal Article	Journal Article	High
12	Norms for a neuropsychological test battery to diagnose dementia in the elderly: A study from Sri Lanka	Journal of Neurosciences in Rural Practice; 2015; 6(2): 177-181	Srinivasan, S; Jaleel, Q	To pilot a neurosurgical battery and provide norms stratified by demographic variables such as age and level of education	Journal Article	Screening (Instrument validation)	High
13	Validation of the Sinhala version of the Montreal Cognitive Assessment in Screening for Dementia	Ceylon Medical Journal, 2011; 56(4): 147 - 153	Karunaratne, S; Hanwella, R; de Silva, VA	To validate the Sinhala version of the Montreal Cognitive Assessment (MoCA) scale in screening for dementia	Journal Article	Screening (Instrument validation)	High

Table 3.2: The summary of included studies and papers (*Cont.*)

S No	Title	Source	Authors	Aim of the Study/ paper	Publication Type	Mapping Category/ Domain	Quality Assessment
14	Validation of a functional screening instrument for dementia in an elderly Sri Lankan population: comparison of modified Bristol and Blessed activities of daily living scales.	BMC research notes; 2010; 3(1): 268	Umayal, S; Kulathunga, M; Somaratne, S; *et al.*	To validate Activities of Daily Living (ADL) scale appropriate for use in assessing the presence of dementia in an elderly population living in care homes in Sri Lanka	Journal Article	Screening (Instrument validation)	High
15	Comparison of three instruments used in the assessment of dementia in Sri Lanka.	Indian journal of psychiatry; 2005; 47(2): 109-112	Kathriarachchi, ST; Sivayogan, S; Jayaratna, SD; Dharmasena, SR	To compare the use of MMSE, IQCODE and CDR in the assessment of patients with dementia in Sri Lanka	Journal Article	Screening (Instrument validation)	High
16	Prevalence of mild cognitive impairment and its selected correlates among elders in Jaffna District: A mixed-method Study	Dissertation and Theses, PGIM; 2015; (D 3959)	Coonghe, P.A.D	To adapt, translate and validate the Tamil version of the MoCA scale and MMSE in screening for MCI To design a tool for identifying MCI among the elderly in a community setting	Dissertation submitted to the degree of MD (Community Medicine)	Prevalence (include a qualitative assessment) Screening (Instrument validation of MMSE and MoCA Tamil versions)	Moderate
17	Alzheimer's disease in Sri Lanka	Journal of the Ceylon College of Physicians, 2003, 36: 14-26	de Silva, HA	To report the author's work on cognitive impairment and dementia for E V Peiris Memorial Oration.	Journal article: Oration Paper	Prevalence Management of dementia Screening (Translating and validating screening Instrument)	Moderate

Table 3.2: The summary of included studies and papers (*Cont.*)

S No	Title	Source	Authors	Aim of the Study/ paper	Publication Type	Mapping Category/ Domain	Quality Assessment
18	Medications used in dementia: a review of evidence	SL J Psychiatry 2015; 6(2): 3-8	Suraweera, C; Hanwella, R; de Silva, VA	To review the evidence regarding the efficacy of cholinesterase inhibitors, memantine and antipsychotics, in the treatment of dementia	Journal Article: Review paper	Treatment	Low
19	Rating Scales validated for Sri Lankan populations	SL J Psychiatry 2013; 4(2): 16-24	Suraweera, C; Hanwella, R; Sivayokan, R; de Silva VA	To identify scales which have been translated into Sinhala or Tamil and validated in a Sri Lankan population. Methods	Journal Article: Review paper	Screening (Instrument and Translation validation)	Low
20	Validation of the Sinhala version of the Repeatable Battery for Assessment of Neuropsychological Status (RBANS)	Ceylon Medical Journal 2016; 61: 163-170	Suraweera CU; Anandakumar D; Dahanayake D; *et al.*	To culturally adapt RBANS and investigate the validity and reliability of culturally adapted RBANS (RBANS-S)	Journal Article:	Screening (Instrument validation)	High
21	Prevalence of behavioural and psychological symptoms of dementia and its association with the degree of cognitive impairment in patients presenting to the National Institute of Mental Health, Sri Lanka	SL J Psychiatry 2016; 7(1): 4-8	Dahanayake, DMA; Isuru, LLA; Aththanayake, NNK; *et al.*	To describe the patterns of BPSD among patients admitted to the National Institute of Mental Health (NIMH), Sri Lanka and its association with the degree of cognitive impairment.	Journal Article: Cross-sectional descriptive Study	Prevalence	Moderate

Table 3.2: The summary of included studies and papers (*Cont.*)

S No	Title	Source	Authors	Aim of the Study/ paper	Publication Type	Mapping Category/ Domain	Quality Assessment
22	Reasons for encounter and existing medical and psychosocial problems of Geriatric patients in a general practice	Dissertation and Theses, PGIM_ Colombo 2004; (D 7663)	Ramanayaka, RPJC	To explore the reasons for medical and psychological problems of elderly patents in an outpatient clinic	Dissertation submitted to the degree of MD (Community Medicine	Screening (for dementia)	Moderate
23	A critical drug review of ingredients of *Sarasvatha* choorna: used as a remedy for dementia	Journal of Innovations in Pharmaceutical and Biological Sciences (JIPBS) 2017; 4(3): 43-47	Karunaratne, TDN; Sugataratana, K; Ariyawansa HAS; de Silva, HA	To review the efficacy of ingredients of an Ayurvedic medication called '*Sarasvatha Choorna*' in the management of dementia	Journal Article: A review	Management of Dementia/ Care models	Moderate
24	Standardization of *Sarasvatha Choorna*: Used as a Remedy for Dementia	American Journal of Clinical and Experimental Medicine 2015; 3(5): 288-292	Karunaratne, TDN; Sugataratana, K; Ariyawansa, HAS; *et al*.	To standardise *Sarasvatha Choorna* by using standard protocols	Journal Article	Dementia Care models	Moderate
25	The frequency of cognitive dysfunction in elderly Sri Lankans with type 2 diabetes mellitus	International Journal of Geriatric Psychiatry 2008; 23: 1205-1206	Rajakumaraswamy, N; Rajapakse, IH; Fernando, DJS	To study the frequency of cognitive dysfunction among elderly Sri Lankans with type 2 diabetes	Journal Article: Research letter	Prevalence Screening Instruments	Low

Table 3.2: The summary of included studies and papers (*Cont.*)

S No	Title	Source	Authors	Aim of the Study/ paper	Publication Type	Mapping Category/ Domain	Quality Assessment
26	Relationship between increased risk of falling and cognitive impairment in residents of an elderly home in the Colombo district	Ceylon Medical Journal 2014; 59: 21-23	Thanthrige, RS; Dassanayake, S; Dissanayake, D	To examine cognitive impairments and evaluate the association between such impairment and risk of falling among a group of residents of an elderly home	Journal Article: Brief report	Screening	Low
27	Cognitive impairment and symptoms of depression among geriatric patients in a tertiary care unit in Sri Lanka	Indian Journal of Psychiatry 2010; 52(3): 279-280	Rodrigo, C; Perera, S; Adhikari, M; Rajapakse, A; Rajapakse, S	To assess the impact of educational level and social support on cognitive impairment	Journal Article: Letter to Editor	Prevalence Screening Care models	Low
28	Care of the elderly: a multidisciplinary approach	Journal of the Ceylon College of Physicians, 2014, 45: 45-48	Samaraweera, DN	To describe the importance of care of elderly and mental status screening in routine elders' clinic in Medirigiriya area (A case vignette)	Journal Article: Opinion paper	Screening	Low

Table 3.3: Domains and sub-domains covered by the studies

Domain → / Study/Paper ↓		Prevalence of Dementia	Pathophysiology	Treatment/ Management	Dementia Care models	Caregiver Burden/Issues/ Challenges/ Experience	Caregiver Skills/Training	Screening (Instruments and Diagnosis Procedure)
1	de Silva, Gunatilake and Smith (2003)	**Y**	**Y**					**Y**
2	Abeywickrema, Weerasundera and Ranasinghe (2015)					**Y**		
3	Williams (2011)					**Y**		
4	Marçal-Grilo (2014)				**Y**		**Y**	
5	de Silva, Pathmeswaran and Gunatilake, (2005)			**Y**		**Y**		
6	de Silva (2005)		**Y**	**Y**				
7	de Silva *et al.* (2005)		**Y**					**Y**
8	Wijesinghe *et al.* (2016)		**Y**					
9	Wijesinghe *et al.* (2017)		**Y**					
10	de Silva and Gunatilake (2002)							**Y**
11	De Silva *et al.* (2009)							**Y**
12	Srinivasan and Jaleel (2015)							**Y**
13	Karunaratne, Hanwella and Silva (2011)							**Y**
14	Umayal *et al.* (2010)							**Y**
15	Kathriarachchi *et al.* (2005)							**Y**
16	Coonghe (2015)	**Y**						**Y**
17	de Silva (2003)	**Y**	**Y**					**Y**
18	Suraweera, Hanwella and De Silva (2015)			**Y**				
19	Suraweera *et al.* (2013)							**Y**
20	Suraweera *et al.* (2016)							**Y**
21	Dahanayake *et al.* (2016)		**Y**					
22	Ramanayaka (2004)							**Y**
23	Karunaratne *et al.* (2017)			**Y**	**Y**			
24	Karunaratne *et al.* (2015)			**Y**	**Y**			
25	Rajakumaraswamy, Rajapakse and Fernando (2008)	**Y**						**Y**
26	Thanthrige, Dassanayake and Dissanayake (2014)	**Y**						**Y**
27	Rodrigo *et al.*, (2010)	**Y**			**Y**			**Y**
28	Samaraweera (2014)							**Y**

Domain 1: Dementia prevalence in Sri Lanka

Among the six papers reported on prevalence three report on dementia prevalence while the others report on mild cognitive impairment (MCI) (See Table 3.3, page 83). De Silva *et al.* (2003) reported the first prevalence study with an overall prevalence rate of 3.98% PwD in Ragama area (95% CI = 2.6% - 5.7%). Among them 20 (71.4%) had probable AD, 4 (14.3%) had vascular dementia, 2 (7.1%) had mixed dementia (AD and VD) and one person (3.6%) had Lewy body's dementia. One participant was diagnosed to have dementia due to syphilis. Advanced age, female gender and illiteracy were associated with a higher prevalence of dementia among the study group of older adults aged 65 years or more (n=703) (de Silva, Gunatilake and Smith, 2003). Another brief report on a study among a group of older adults (n=50) aged 60 – 85 years reported that 66% demonstrated mild to severe cognitive deficits and 44% of elders demonstrated moderate to severe cognitive deficits according to MMSE (Thanthrige, Dassanayake and Dissanayake, 2014). However, this brief report does not include any information on dementia diagnosis.

Dahanayake *et al.* (2016) reported the severity of mild (32.8%), moderate (42.6%) and severe (24.6%) dementia respectively among a sample of 122 patients diagnosed with dementia in Colombo (mean age 71.3%, the mean duration of cognitive impairment was 2.9 years). The majority of PwD presented with BPSD including delusions (42.6%), irritability (41%), appetite changes (34.4%) and depression (32%). This study also reported depression and anxiety symptoms were common among people with mild dementia.

Rajakumaraswamy, Rajapakse and Fernando (2008) reported a high rate of cognitive impairment (32.8%) and dementia prevalence (11.8%) among an elderly population

(n=204) with type II Diabetes in Sri Lanka. A study conducted among a group of older adults who attended clinics in National Hospital- Sri Lanka revealed a high prevalence (50%) of cognitive impairment; however, there was no association found between the severity of cognitive impairment and the older adults' education level or social support (Rodrigo *et al.*, 2010).

Unpublished data from an MD thesis on prevalence of MCI and selected correlates among elders in Jaffna district reported a relatively high prevalence of MCI (20.9% with 95% CI = 18.4 - 23.4) among elders in Jaffna (Coonghe 2015).

Table 3.4: Summary of prevalence studies

Paper	Study Design	Study setting	Screening tools used	Sample size	Participant characteristics	Prevalence of dementia/MCI*	Remarks
De Silva *et al.* (2003)	Descriptive Survey	Ragama	Phase 1: MMSE Phase 2: Clinical Diagnosis of AD/ CAMCOG/ CAMDEX	703 28	older adults aged 65 years and over	Total 3.98% 95% CI (2.6-5.7) Male 3.3% Female 4.4%	-
Rajakumaraswamy *et al.* (2008)	Descriptive Survey	-	MMSE CAMCOG CAMDEX	204	85 male, 119 female Mean age = 63.6 (8.3 SD)	11.8% *32.8%	Increased risk of developing AD and VD in people with type II diabetes
Rodrigo *et al.* (2010)	Prospective study	Colombo	MMSE	100	older adults aged 65 years and over Mean age = 71.1 (6.32 SD)	*50%	-
Thanthrige *et al.* (2014)	descriptive analytical study	Colombo	MoCA MMSE	50	older adults aged 60-85 years	*66%	High risk of fall among people with cognitive impairment (p <= 0.002)
Coonghe (2015)	mix-method study	Jaffna	MoCA_Tamil version MMSE_Tamil version	400 Qualitative phase (n=16)	older adults aged 65 years and over	*20.9% 95% CI (18.4-23.4)	High prevalence of MCI among elderly in Jaffna
Dahanayake *et al.* (2016)	Cross-sectional descriptive Study	Colombo	MMSE NPI	122	older adults with dementia	32.8% mild, 42.6% moderate and 24.6% severe	-

Domain 2: Pathophysiology

There were only four papers on the pathophysiology of dementia including one low-quality opinion paper, one moderate quality journal article, one moderate quality conference proceeding from the same study and one moderate quality thesis. De Silva *et al.* (2004) first reported high mean plasma homocysteine (tHcy) levels, presence of apoE4 allele and MTL atrophy are associated with a study population of people with Alzheimer's disease in Sri Lanka (n= 23 patients with AD and 21 control). The study found a significant increase in mean plasma tHcy levels ($p = 0.001$) and frequency of apoE4 genotype ($p = 0.003$) among people with AD. Wijesinghe *et al.* (2016) conducted the first autopsy study to investigate genetic polymorphisms using 76 post-mortem brain samples of older adults in Sri Lanka and India. Findings indicated that ageing cytoskeletal pathologies are higher in elderly Sri Lankans when compared to Indian older adults; perhaps due to their age, illiteracy and genes (e.g. apoE4 and thal β-amyloid phase) are significantly associated in determining the aetiology of AD. Wijesinghe *et al.* (2017) reported that genetic, dietary and/ or environmental variations are associated with ageing cytoskeletal pathologies among older adults in Sri Lanka.

Coonghe (2015) reports socio-demographic factors (such as Age >75, education less than 10 years, unstable income) and habitual risk factors (such as beetle chewing, night-time sleep less than seven hours, vegetarian dietary pattern, not involving any kind of socialisation activity) were found to be the correlating factors for MCI. Even though MCI is different from dementia these findings are important as the MCI can progress to dementia.

Domain 3: Screening for dementia

Screening older adults for Dementia and Cognitive Impairment

Samaraweera (2004) writes that most of the general elders' clinics in Sri Lanka had missed detecting cognitive impairment and dementia among elderly patients due to time constraints and lack of emphasis on the systematic evaluation of the elderly. Samaraweera (2004) also highlights a need for using specific screening tools in general clinics to detect geriatric psychological problems among older adults. Further to this, in his thesis, Coonghe (2015) reports diagnosis by the consultant neurologist is the gold standard for diagnosis of MCI including Alzheimer's disease.

Screening tools used in the studies

The Mini-Mental State Examination (MMSE) is the most common screening tool used to detect cognitive impairment of older adults. This tool has been translated and validated for both Sinhala (Thanthrige *et al.* 2014; De Silva *et al.* 2005; De Silva *et al.* 2003) and Tamil Languages (Rajakumaraswamy, Rajapakse and Fernando, 2008; Coonghe, 2015). Clinical diagnosis is mostly based on DSM IV, ICD 10 and NINCDS-ADRDA criteria which included structured neuropsychiatric assessment using Cambridge examination for mental disorders of the elderly (CAMDEX), Cambridge Cognitive Score (CAMCOG), Montreal Cognitive Assessment (MoCA), Neuropsychiatric Inventory (NPI) (de Silva, Gunatilake and Smith, 2003; Dahanayake *et al.*, 2016), Clinical Dementia Rating (CDR) scale (Umayal *et al.*, 2010), laboratory investigations and axial CT scan of the brain and an informant interviews (De Silva *et al.,* 2005; De Silva *et al.,* 2003). Authors also report using biochemical screening and neuro-imaging tests such as CT and MRI for the detection of dementia types and to exclude other causes (Suraweera *et al.,* 2016).

Translating and validating of instruments for Dementia Screening

The majority of the studies included in this review were instrument validations. There were eight studies on translating and validating of dementia screening tools (de Silva and Gunatilake, 2002; Kathriarachchi *et al.,* 2005; Kulathunga *et al.,* 2010; Karunaratne, Hanwella, De Silva 2011; Coonghe, 2015; Sirinivasan and Jaleel, 2015 and Suraweera *et al.,* 2016).

The MMSE is the first Sinhala translated and validated screening tool with culturally appropriate modifications of the content. Sensitivity and specificity of the translated MMSE was reported as 93.5% and 84.6% respectively (with cut off value of 17)(de Silva and Gunatilake, 2002; de Silva, 2003). The authors reported that the translated version is a useful and sensitive instrument to screen for cognitive impairment in Sri Lanka. A Tamil translation and criterion validity of MMSE has been assessed by Coonghe (2015); the area under the ROC was 0.85 (95% CI 0.80 – 0.89).

Karunaratne, Hanwella, De Silva (2011) translated the MoCA into Sinhala for the first time. Validation of Montreal Cognitive Assessment (MoCA) reported a sensitivity of 100% and specificity of 87% in detecting mild Alzheimer's disease at a cut-off of 26 with a sensitivity of 90% in detecting MCI. A Tamil translation and criterion validity of MoCA has been assessed by Coonghe (2015) for MCI (mean score = 21.16; SD+- 2.55) and AD (mean score = 14.05; SD+- 3.81); there was also a high correlation between MoCA and MMSE Tamil versions (0.853). The area under the ROC was 0.87 (95% CI 0.83 – 0.91).

Kathriarachchi *et al.* (2005) compared the use of the Sinhala version of MMSE, IQCODE and CDR scales and found these to be sensitive and culturally adapted screening tools for dementia in Sri Lanka. Umayal *et al.* (2010) validated two scales: modified Bristol

and Blessed Activities of Daily Living (ADL) scale and reported the scales. The scales were found to be highly sensitive and specific for detecting dementia among older people living in care homes in Sri Lanka. The modified Bristol scale (area under the ROC: 0.933) was reported as being a better instrument than the modified Blessed scale (area under the ROC: 0.892).

Suraweera *et al.* (2016) validated and culturally adopted the Sinhala version of the Repeatable Battery for Assessment of Neuropsychological Status (RBANS). The authors report currently used MMSE and Montreal Cognitive Assessment (MoCA) scales are difficult for people with cognitive impairment to complete and also insensitive to mild cognitive impairment. Authors report RBANS is sensitive in detecting both mild and severe cognitive impairment when compared to MoCA and MMSE tools. The study shows RBANS total scale correlated highly with MMSE total score, (Pearson correlational coefficient = 0.793; p = 0.01). The sensitivity and specificity for RBANS was 89% and 85%, respectively, at a total score of 80.5 (reliability coefficient was 0.929).

Domain 4: Dementia management in Sri Lanka

Current situation of dementia care in Sri Lanka

De Silva (2005) has highlighted the importance of starting a national programme to tackle dementia in Sri Lanka. De Silva (2005) stated that in the absence of formal care services for PwD in Sri Lanka, there is a heavy reliance on informal care. However, the credibility of the findings reported in this opinion paper is uncertain due to the lack of empirical evidence. Availability of specific drugs for all the diagnosed patients, developing support and care programmes for patients and family caregivers, and further research was recommended to address the issue at a national level.

Kuruppuarachchi and Lawrence (2006) argued that the Sri Lankan health system is lacking in health care services such as; providing emotional support, advice on practical and emotional aspects of caring, coping and loss, and keeping a balance between caregivers' personal life and their caring role. Samaraweera (2014) states that Sri Lanka does not have a structured programme for detection and management of problems or conditions that are common among the elderly even though it has a National Policy for Elders. Rodrigo *et al.* (2010), in a letter to a journal, highlight the importance of improving mental health among older adults, the need for coordinating psychiatric and medical care to reduce disease burden and the need for routine screening of elderly people for cognitive impairment. Samaraweera (2014) contributes to this by suggesting a system to detect psychogeriatric problems such as dementia and depression at general out-patient clinics for older adults and to refer them to relevant professionals for further evaluation and treatments of the detected conditions; and also, to develop services both in acute and primary care settings.

Williams (2011) states in a conference abstract that 'developing a cost-effective, sustainable and equitable service for older adults with dementia is a challenge in Sri Lanka'. His suggestion is to deviate from the medical model and to focus on implementing a social model of care for PwD in collaboration with families and the community. The author further stresses that the westernised 'resource-hungry models' applied in high-income countries would not be applicable to Sri Lanka. Samaraweera (2014) suggests integrating volunteers from elders' societies, village leaders, social workers with health care professionals in both community and hospitals to care for both affected older adults and their caregivers and also to enable quality care for the elderly in Sri Lanka. The authors also stress the importance of non-

pharmacological interventions when managing PwD (Coonghe, 2015). Coonghe (2015) recommends community-based activities need to be implemented to control the MCI among older adults. According to the experience and observations of Marçal-Grilo (2014) (a volunteer community dementia nursing specialist), most of the dementia care provision is limited to the city of Colombo and provided primarily in the hospital setting rather than via community–based services. Marçal-Grilo (2014) writes that the 'medical model is practised widely and considered as the best approach currently due to limited numbers of nurses and doctors available in the older age care'. The author argues that encouraging nurses to take part in community-based dementia care services is 'challenge worthy' as the number of PwD increases, and encouraging informal care may leave more room for new care models in managing dementia within local communities (Marçal-Grilo, 2014).

In addition to the government services, Marçal-Grilo (2014) discusses the work of the Lanka Alzheimer's Foundation (LAF), which acts as a non-governmental, charity organization to advocate and support the needs of PwD and people with cognitive impairment and their family members. The main activities of this organization include producing information in dementia, offering confidential support, training and psychological support for the informal caregivers, cognitive stimulating activities for PwD, programmes to reduce the level of stigma such as challenging some of the beliefs of dementia and encouraging open dialogue. However, these services are only centralised in the district of Colombo.

Among the included records, two articles describe the Ayurveda care model in treating dementia in Sri Lanka (Karunaratne *et al.*, 2015, 2017). The authors report that medicinal and nutraceutical properties of ingredients of their Ayurveda drug called

Sarasvata Choorna have memory enhancement and antidepressant qualities therefore the new drug may be used in the management of dementia and Alzheimer disease. *Sarasvata Choorna* is a herbal preparation which consists of 12 medicinal plants and rock salt.

Caregiver Characteristics

Abeywickrema *et al.* (2015), de Silva (2005) and Kuruppuarachchi and Lawrence (2006) all highlight that caring for PwD in Sri Lanka is mainly done by the family members. Abeywickrema *et al.* (2015) report the majority (71.4%) of informal caregivers were female (37.7% daughters and 21.1% wives) and 11.7% of them were over age 65 (mean age = 49 years). 83.1% of informal caregivers lived in the same household (sample size = 77).

Issues and Challenges of Caregiving

Samaraweera (2014) argues that not having a systematic referral system within the current health care system delays the identification of dementia and impairs the health services for PwD and their families. The following challenges were identified in the formal, community and home-based care settings when providing care services to PwD by Marçal-Grilo (2014):

- No professional assistance for families who are living with a PwD
- Diagnoses at the community level are difficult as specialist dementia care services are scattered or not available.
- Power struggles and resistance to change among health care professionals.
- Authoritative expert role among some health professionals offers little room for multidisciplinary approaches to dementia care.

- Health information and knowledge is considered as 'resources to hold on to' rather than share with PwD or family members

Concerning informal caregiving, Marçal-Grilo (2014) identified the lack of understanding of behavioural problems, lack of access to health care, shame and stigma, limited support in the caregiving role, and emotional and practical aspects of caregiving as the main challenges faced by informal caregivers. Marçal-Grilo (2014) stated that memory loss and disorientation is commonly mistaken as a part of normal ageing, the signs and symptoms are usually ignored until the issues become unmanageable. The author reports that dementia often drags families into social deprivation and poverty, and contributes to inequalities in society and access to health care.

Thanthrige, Dassanayake and Dissanayake (2014) report that older adults with severe cognitive impairment have a significantly higher falling tendency ($p = 0.001$). In their study, the older people with cognitive impairment demonstrated poor functional lower extremity strength and balance, with a positive correlation observed between the cognitive function and lower extremity strength ($r = 0.469$, $p = 0.001$).

The perceived stigma around mental illness has been found to be the main obstacle for seeking help and medical advice (Marçal-Grilo, 2014). According to Kuruppuarachchi and Lawrence (2006), looking after older adults with dementia within the family is becoming a challenge in Sri Lanka as the traditional 'closely-knit' family structure is changing due to demographic transitions such as the increased tendency for nuclear families and migration for employment.

Abeywickrema *et al.* (2015) focus specifically on caregiver burden. In their study sample (n = 77), 43% were experiencing mild to a moderate burden, 26% were experiencing moderate to severe level of carer burden and 6.5% of the family caregivers reported a severe burden. The increased age of the caregiver and lack of family support increased the caregiver burden while increased household income significantly reduced the burden of care. Marital status and employment status of the caregivers were not associated with caregiver burden. According to their study, there was no association between caregiver burden and Behavioural and Psychological Symptoms of Dementia (BPSD) of the affected older adults. There was no significant association between the level of caregiver burden and the presence of depression ($p = 0.31$). However, 3.9% of the study participants presented with major depression when screened (Abeywickrema *et al.,* 2015). De Silva *et al.* (2005) investigated the efficacy of treatment for people with AD with rivastigmine for 20 weeks, finding that this produces a significant improvement in their ADL functioning ($p < 0.001$), and subsequently lowers the caregiver burden.

Skills in dementia care

According to Marçal-Grilo (2014), specialised care for older adults is in the hands of a limited number of health professionals and the percentage of nursing staff working directly with those aged 65 years and above is unknown. Based on the author's observations during his volunteer work in Sri Lanka Marçal-Grilo (2014) reports that specialised dementia support is 'patchy and limited' due to a lack of formal post-registration training in old age care and mental health for nurses in Sri Lanka. Samaraweera (2014) suggests including the study of geriatrics as a mandatory

requirement in undergraduate and postgraduate curricula in order to improve the knowledge and skills among nurses, doctors and paramedical professionals.

3.6 Discussion and Chapter summary

A total of 28 records on dementia-related studies specifically looking at older adults conducted in Sri Lanka were identified and included in the narrative synthesis in the review. The papers reviewed were mapped across four results-generated domains: epidemiology, pathophysiology, screening for dementia, and dementia management. The International Consortium for Health Outcome Measurement (ICHOM) standard set for dementia (https://www.ichom.org/portfolio/dementia/) recommends a set of domains which highlights the outcomes that matter most to persons with dementia. These five broader domains include: Symptoms, functioning and quality of life, carer, sustainability, safety and clinical status of the person with dementia. When compared to these domains, the evidence extracted from the current systematic review indicated that most of the aspects are missing in Sri Lankan dementia literature. It appeared that the aspects related to carers and the people with dementia (e.g. quality of life, wellbeing, full-time care engagement, falls, hospital admissions, disease progression and overall survival) have not yet been explored in the Sri Lankan context.

Results indicate that the dementia prevalence has been studied only in three districts in Sri Lanka: Matara, Colombo and Jaffna (de Silva *et al.,* 2003; Gunaratne, 2009; Coonghe, 2015; Dahanayake *et al.,* 2016). However, there are limitations of these studies, such as small sample size, high dropouts (de Silva *et al.,* 2003) and no community samples (Dahanayake *et al.*, 2016); leading to these records being appraised as low-quality.

The review found a few studies reporting on dementia care management, and only one on caregiver burden in Sri Lanka. The only study conducted among the informal caregivers was a descriptive survey by Abeywickrema *et al.* (2015) using the ZBI questionnaire with a sample size of 77, and the researchers had not assessed the early issues and challenges of caregiving as they excluded the caregivers of PwD diagnosed for less than 6 months. The other articles on caregivers were opinion papers and conference abstracts. The overall quality of the 28 included records was poor and lower strength of evidence means that it is not possible to draw any firm conclusions from the data available.

Most records (13) were classified in the domain of 'screening for dementia' and among them, eight were on translating and validating of screening instruments. It appeared that the MMSE is the most common screening tool used in the reviewed studies. A recent systematic review reports that MoCA is more sensitive than MMSE for dementia screening (De Roeck *et al.*, 2019). However, the practical application of some of these tools in assessment and screening for dementia during general clinic settings was minimal and less reported. It was observed that the translation-back-translation method has been used to translate the instruments to local languages (de Silva and Gunatilake, 2002; de Silva, 2003). Sumathipala and Murray (2000) suggested that 'group method' (will be explained in Methodology Chapter, Section 4.2.4, pages 114 - 116) is better than the translation-back-translation method for cross-cultural adaptation of study instruments as it can minimise the drawbacks of translation issues such as term ambiguity through discussion. According to 10/66 dementia study group, information variance, absence of population norms, differences in data collection tools

and lack of resources to conduct detailed neurological tests in LAMIC prevent comparisons of findings with other settings (Ferri and Jacob, 2017).

Although dementia literature continues to expand, the research output from Sri Lanka is limited. This review revealed that research gaps exist in areas such as dementia care, characteristics of formal and informal caregivers, and service provision for people and families with dementia. There is a need for high-quality research, as well as more empirical research, as several of the papers included in the review are opinion pieces, conference abstracts or letters to journal editors. It has also been argued that there is a need for more studies on the elderly concerning improving the health services such as conducting a psychological screening of older adults as routine clinic activities. Kuruppuarachchi and Lawrence (2006) write in their opinion piece 'there is a dearth of research related to dementia caregiver burden in Sri Lanka'. Abeywickrema *et al.* (2015) argue that further research on dementia caregivers is needed in Sri Lanka in order to identify the true magnitude of the caregiver burden, issues and challenges and to develop services and support for caregivers.

Even though prevalence, caregiver burden and challenges of caregiving are universally reported, current information and research on the caregiver experience is lacking in Sri Lanka as with other developing countries. Information at a localised level is important, because emerging evidence suggests different models of care exist within different cultural contexts. For example, Prince *et al.* (2012) show that the majority of studies and caregiving models on dementia predominantly come from developed western countries. Also, the studies have shown significant differences in how caregivers perceive the caregiving role for those with dementia in different countries

(Pattanayak *et al.*, 2010; Hughes, 2013; Schoonover *et al.*, 2014; Wang *et al.*, 2014; Wijeratne, 2015).

The gaps identified through this systematic review regarding the lack of empirical research on dementia caregiving in Sri Lanka – and particularly in informal settings where there have been no studies to-date– provides a strong rationale for the present study.

3.7 Research question, Aim and Objectives of the study

3.7.1 Research question

The thorough literature review on dementia and caregiving for PwD (outlined in Chapter Two) and the systematic review on dementia research activity in Sri Lanka identified the significant research gap in the context in relation to informal caregiving. There is a compelling need to explore the perspectives of informal dementia caregiving, including the views and experience of the family caregivers who are providing long-term care for PwD. Therefore, when conducting this study, I decided to follow an exploratory approach informed by phenomenology; and based on the gaps identified the following research question was developed:

- What are the views, perceptions and experiences of informal caregivers for older adults with dementia in Sri Lanka?

3.7.2 Objectives of the study

The following objectives were developed to best address the research question:

1. To describe the meaning of dementia and the meaning of caregiving to informal caregivers within the Sri Lankan context.

2. To explore care practices and experience of the informal caregivers living with an older adult with dementia within the Sri Lankan context.

3. To explore the concerns, issues, challenges and caregiving needs among informal caregivers over the course of illness.

Chapter 04

Methodology

This chapter describes the research methodology adopted in this thesis. The chapter begins with an overview of the exploratory research approach and the philosophical background. Then I will proceed to a discussion of the epistemological stance, the rationale for selecting an interpretivist approach and a phenomenological research design for this thesis, the theoretical basis for the methods used in sample selection, data collection, data analysis, synthesis and interpretation of the findings and the ethical considerations involved in the study. This chapter also includes my reflections on the issues of trustworthiness and attempts to address these.

4.1 Exploratory approach as the research design

The current study focused on understanding the views, perceptions and experiences of informal caregivers for people with dementia (PwD) with an emphasis on how they conceptualised the meaning of dementia and caregiving, and described their lived experiences based on their socio-cultural context. Evidence shows an inductive, exploratory approach is the most appropriate for attempting to understand an individual's experience (Avison and Malaurent, 2015); especially when a little or nothing is known about the phenomenon studied (Burnard *et al.*, 2008; Harper, 2012). As described in Chapter Three, existing evidence on dementia caregiving is minimal in the study setting and it was more appropriate to develop exploratory research questions, rather than formulating a hypothesis. Exploratory approaches are also appropriate when developing theory to account for these experiences (Robinson, Tang and Taylor, 2015).

Exploratory approaches commonly draw on qualitative methods, which can allow the researcher to delve into the 'essence of the topic 'and can have the emancipatory potential of 'giving voice' to groups of people who are rarely heard (Robinson, Tang and Taylor, 2015; Bloomberg and Volpe, 2017), as is the case in the current thesis. Therefore, an exploratory research design is most suitable and will provide understanding of the phenomenon of interest in the current study. The key concepts discussed in the following sections will set the background for the qualitative research design selected. I will explain how this fit with the scope and aims of this thesis.

4.1.1 Ontological and Epistemological position

Distinction between realism, critical realism and relativism

Ontology determines the relationship between the world, human interpretations and practices which ranges along a continuum from 'realism', 'critical realism' to 'relativism' (Braun and Clarke, 2013; Avenier and Thomas, 2015). Realism is the ontology underpinning most quantitative research, and most qualitative research is underpinned by a relativist or critical realist ontological positions. Realism, also known as the 'mind-independent truth', is entirely independent of human ways of thinking about reality. Relativism is described as a view where reality is entirely depended on human interpretation and knowledge (Braun and Clarke, 2013); accordingly, there are multiple constructed realities. Critical realism, which sits in between realism and relativism is commonly adopted in qualitative research. According to the seminal work of Bhaskar (1978), critical realism postulates that the conception of the world is composed of 'generative mechanisms and structures' (for example, social structures), existing independently from each other, but capable of

producing ‘patterns of events’ that we observe (the actual domain). The domain of experienced events is called the ‘empirical domain’ (Bhaskar, 1978).

Critical realism invokes a real and knowable world which ‘sits behind the subjective and socially located knowledge’ a researcher can access (Madill and Gough, 2008; Gorski, 2013). Bhaskar (1978) argues that critical realism prescribes social scientific method which seeks to identify ‘the mechanisms producing social events, but with a recognition that human agency is made possible by social structures’ that themselves require the procreation of certain actions. The crux of critical realism is that the social world is both socially-constructed and real; however, social phenomena (actions, meanings or language) exist regardless of interpretation (Avenier and Thomas, 2015; Parr, 2015). According to Braun and Clarke, (2013) knowledge can be socially influenced and reflected as a separate reality which only partially accessible. It would therefore be like ‘looking at a view through a prism, so what is seen is nuanced by the shape of the prism’ where the prism can be culture, history or religion (Braun and Clarke, 2013, p.28).

I adopt a critical realist position in this thesis. Dementia and its signs and symptoms are natural, biological phenomena (which is real and objective); but the meanings and lived experiences of dementia and caregiving are constructed according to caregivers’ interpretations that are based on their socio-cultural and religious contexts (which is subjective). Therefore, critical realist position that sits in the middle is suitable for this thesis as it combines the objective and subjective aspects of the phenomenon being studied. Knowledge is developed by exploring and understanding the social world of the people being studied; focusing on their meaning and interpretations (Lincoln and Guba, 1985; Bryman, 2012).

Distinction between the Constructionist and Constructivist approaches

The postmodern perspective is that both knowledge and reality are subjective. Both social constructionism and constructivism endorse a subjectivist view of knowledge (Amineh and Asl, 2015). Social constructionists believe that the knowledge and reality are constructed and re-constructed by people in a specific context through discourse and social interactions (da Silva, Carrieri and de Souza, 2012; Sommers-Flanagan and Sommers-Flanaga, 2018). Rather than inputs and/ or outcomes of mediating processes, construction of identities and relationships are considered as ongoing relational realities in human inquiry (Hosking and Pluut, 2010). In this context, knowledge and reality is not external and pre-given, but instead it is a mutual social construction that emphasises the process through which meanings are constructed.

In contast, constructivism emphasises the individual's biological and cognitive processes of constructing meanings. Constructivists believe that knowledge and reality are constructed within individuals. For example, according to Jean Piaget, individuals make sense of new information or experience reality by associating it with what they already know (Sommers-Flanagan and Sommers-Flanaga, 2018). However, according to social-constructivist perspectives (e.g. Lev Vygotsky), the process of knowing is affected by other people and is mediated by their language, thoughts, community and culture (Amineh and Asl, 2015). Therefore, in line with a critical realist position, I chose the social-constructivist approach for this thesis as it relates to the phenomenon studied, that is the lived experience of a group of informal dementia caregivers.

Epistemological position in this thesis

Epistemology determines what counts as the valid and true knowledge and, conversely what is seen as not valid knowledge (Braun and Clarke, 2013). The current thesis adopted an interpretivist and social constructivist epistemological position. Exploratory research commonly emanates from interpretivist or a social constructivist epistemological position (Makombe, 2017). Interpretivism is characterised by the social constructions of humans who 'apprehend the world through interpretive activity' (Ferguson, 1993). Interpretivism views knowledge as application of ideas to organise human experience, and emphasises the idea that the empirical world of the individual is not distinct from his or her social interactions with it (Kant, 2007). According to social constructivists the social world is holistic and complex, the individual seeks an understanding of the world in which they live and work, and they develop subjective meanings of their experiences based on their social, cultural, moral, ideological, political or historical context (Braun and Clarke, 2013; Bloomberg and Volpe, 2017). Interpretivism is informed by the idea that meaning is subjective, and highlights the importance of interpretation and observation when understanding the social world. Constructivism emphasises that the knowledge is constructed by human beings through active interactions with the social world including culture, religion, history and values (Yeo, Ritchie, *et al.*, 2014). I understand the critical realism acknowledges both objectivity and subjectivity. However, in this thesis, I link the above epistemological approach to the critical realistic position in terms of subjective, socio-cultural construction of knowledge (i.e., meaning and experience of dementia and caregiving), but not in terms of the objective presence of disease and its symptoms.

In addition to critical realistic position, I also link existentialist perspectives in the discussion as these shared philosophical roots facilitate understanding of the findings of current thesis. Existential perspectives are deeply intuitive, and assume an interpretive or phenomenological perspective to understand the context as whole through the perspectives of the people involved – the informal caregivers, their family members and persons with dementia. According to existentialist perspectives, humans are capable of 'discovering and creating meaning' as they have the power to 'symbolise' and 'transcend the boundaries' of their past, present and future (Farran, 1997).

Accordingly, my epistemological positions for this study can be formulated as follows: (a) data were focused on the perspectives and lived experiences of people who are engaged in informal caregiving for older adults with dementia in Sri Lankan context; (b) I interacted with the participants to explore the subjective meanings of dementia and their caregiving experience; (c) I attempted to understand how the participants themselves make sense of their experiences through the lens of their socio-cultural context, (d) the research process was largely inductive and the interpretations were grounded in the views expressed by the participants and, (e) the claims of findings were drawn through researcher's engagement with the data, reflexivity and existing evidence in the literature. These will be further discussed in the following sections.

4.1.2 Rationale for selecting a qualitative approach

Qualitative research is 'a form of social inquiry that helps in understanding the complex social realities of an individual, groups or various cultures' (Lincoln and Guba, 1985; Schwandt, 2000). The focus of qualitative research is to explore, understand and interpret the social environment, behaviour, perceptions and experiences of

individuals in a particular context by allowing the researcher to enter the participants' socio-cultural world at a particular point in time (Lincoln and Guba, 1985; Schwandt, 2000; Braun and Clarke, 2013; Voils *et al.*, 2008; Creswell, 2013).

It appeared that a qualitative approach is more appropriate to use in the current study. Qualitative research facilitates seeking a deeper understanding of a studied phenomenon, which may not be gained through using quantitative measures such as questionnaires and surveys (Braun and Clarke, 2013; Creswell, 2013). Qualitative approaches are flexible; relatively open and unstructured ways of exploring a social phenomenon may bring unexpected concerns and perspectives of the participants which may have a significant importance (Bryman, 2012). Accordingly, the qualitative approach used in this thesis allowed me to explore and understand deep and complex meanings of dementia and caregiving experience.

4.1.3 Adoption of phenomenology as the methodological approach for the current study

A phenomenological approach was adopted as the methodological position in this thesis. Phenomenology is both a research approach and a philosophical discipline central to the interpretive paradigm (Wojnar and Swanson, 2007).

4.1.3.1 Phenomenology: an overview

Phenomenology is the reflective study of lived experience (Given, 2008). Phenomenology focuses on describing the essence of the meaning of particular phenomenon, concept or idea from the viewpoint of the individuals who experience it (Smith, Flowers and Larkin, 2009). Schutz writes, phenomenology is the study of 'phenomena' or the way experience is understood from the first-person point of view (Schutz, 1976). In other words, a main characteristic of phenomenology is the study of

the 'lifeworld', i.e., the world of immediate experience or natural or original experience of an individual before he conceptualises, theorises or reflects on it (Given, 2008, p. 617). The German philosopher, Edmund Husserl (1859 - 1938) is considered as the founder of phenomenology as a philosophy and the descriptive approach to inquiry. Husserl (1970) defined phenomenology as 'the science of the essence of consciousness':

> *"Putting it in brackets shuts out from the phenomenological field the world as it exists for the subject in simple absoluteness; its place, however, is taken by the world as given in consciousness (perceived, remembered, judged, thought, valued, etc.)" (Husserl, 1970)*

Husserl argued that people can be certain about how things appear in, or present themselves to, their consciousness (Husserl, 1970; Eagleton, 1983). In other words, Husserl appears to be saying that the external world is reduced to the contents of personal consciousness by ignoring anything outside the immediate experience in order to arrive at certainty. Therefore, realities can be treated as pure 'phenomena' and the absolute data from where to begin (Groenewald, 2004). Martin Heidegger (1889 - 1976), a student of Husserl, introduced the concepts of 'being there' and the dialogue between an individual and his/ her 'lifeworld' (Schwandt, 1997) shifting phenomenology from descriptive to interpretive (also called hermeneutic) exercise (Bloomberg and Volpe, 2017). Context was a central concern for Heidegger, which means the understanding of individuals' 'lifeworld' is associated with culture, social context, or historical period in which they live (Wojnar and Swanson, 2007). The idea that the 'human world comprises various aspects of meaning' was brought by Alfred Schultz (1899 - 1956) (Vandenberg, 1997).

Making sense of the world and creating 'meaning' are socially constructed and must be understood within 'typifactory schemes' (that is; the stock of knowledge individuals bring that allows them to typify one another and to communicate) embedded within the social context and it is constructed in on-going relations between people through a dialectical process in day-to-day interactions (Morse, 1987). Therefore, meaning can be considered as an inter-subjective phenomenon. Schutz, (1976) writes:

> *"The world and [participants'] experience of the world make sense for them just as it does for you and for me and for every rational being. This usage of "sense" or "meaning" signifies no more than that a rational being takes up a certain attitude toward any object he may confront." (p.32)*

The principle of phenomenological inquiry is that the experience of the individuals should be examined in the way that it occurs (Smith, Flowers and Larkin, 2009), to identify and understand a given phenomenon from the perspective of those who experience it (Wojnar and Swanson, 2007; Husserl, 1970). The detailed description of different aspects of experience are described and interpreted through language (Davidsen, 2013) in order to identify the essence of 'lived experience', i.e., experience as individuals live through it and recognise it as a particular type of experience (Given, 2008, p. 616) or phenomena from the perspective of those individuals (Creswell, 2013; Bloomberg and Volpe, 2017). The concept of 'lived experience' forms the main epistemological basis and methodological significance for phenomenology (Given, 2008).

4.1.3.2 Rationale for using a phenomenological methodology

Qualitative researchers use different methodological approaches such as grounded theory (GT), ethnography, case study approach, narrative research, phenomenological

approach and participatory action research (PAR) (Carter and Little, 2007). Carter and Little, (2007) stated that the methodology chosen directs the researchers' overall strategy for formulating, articulating, analysing and evaluating the methods used in their research. The rationale for selecting the methodology is based on the research question, aims and objectives of the study (Braun and Clarke, 2013), as well as the fit with the broader ontological and epistemological position taken towards the research. In general, all of these methodological approaches focus on socio-cultural phenomena of everyday life, human experience and the nuances of different human languages; knowledge is generated via interaction between the researcher and the study participants (Denzin, 1989).

In comparison with other qualitative research approaches within interpretivist and social-constructivist paradigms, a phenomenological study based on the philosophy of Husserl and Shultz was considered the most appropriate for addressing the research question – 'What are the views, perceptions and experiences of informal caregivers for older adults with dementia in Sri Lanka?'

Evidence suggests that a phenomenological approach allows researchers to see things in a manner that enriches their understanding of the 'lived experience' of the participants (Groenewald, 2004; Larkin, Watts and Clifton, 2006; Ali and Bokharey, 2015; Meyer, Cullough and Berggren, 2016). It also allows the essence of experience to emerge from the data and highlights what makes an experience unique to each individual (Carter and Little, 2007; Yeo, Ritchie, *et al.*, 2014). The purpose of this thesis was to develop a contextual understanding of family caregivers' perceptions and lived experiences towards home-based dementia caregiving, to see the phenomenon of informal caregiving through their lived experiences and to explore the 'essence of

meaning' of dementia and caregiving in Sri Lankan context. There was no attempt to generalise the experiences, but to interpret the individual experiences which may enhance the awareness of what these lived experiences mean to each caregiver. The phenomenological approach facilitated understanding of caregivers' beliefs, thoughts, attitudes and assumptions towards dementia and caregiving.

4.1.3.3 Theoretical underpinnings of Interpretive Phenomenological Analysis

Interpretive phenomenological analysis (IPA) can be considered as a 'stance' or perspective rather than a distinct 'method' of qualitative data analysis (Larkin, Watts and Clifton, 2006). There are two aims to keep in mind when selecting an IPA approach: (1) the phenomenological requirement to understand the participants' world and 'give voice' to their concerns (descriptive phenomenology), (2) the interpretative requirement to contextualise the initial descriptions in relation to the wider socio-cultural or theoretical context in order to 'make sense' of these claims by providing critical and conceptual commentary upon the participants' experiences (interpretative phenomenology)(Smith and Osborn, 2008; Harper, 2012; Larkin, Watts and Clifton, 2006). Descriptive phenomenology prioritises the 'essence of subjective experience' of the participants, as researchers avoid imposing their own views or understanding of phenomena on to the data. The interpretative phenomenology gives an opportunity to think about 'what it means for the participants' to have expressed their views, perceptions and lived experiences.

IPA is considered as the most suitable method to understand the lived experiences of the caregivers, in their own voice, in their own socio cultural background (Steeman *et al.*, 2006; Smith, Flowers and Larkin, 2009; Peacock, 2011; Smith, 2017). IPA is characterised by a set of common processes which can be applied flexibly, according

to the analytic task (Larkin, Watts and Clifton, 2006). The views and experiences of the informal caregivers were described in their own words, and the findings were interpreted in accordance with the socio-cultural context in Sri Lanka. I will further explain the use of IPA as my method of data analysis in section 4.2.8.

4.2 Study design

This section includes a description of the study population, study setting, the recruitment criteria, recruitment process, data collection and proposed data analysis. Figure 4.1 outlines an overall summary of the study design.

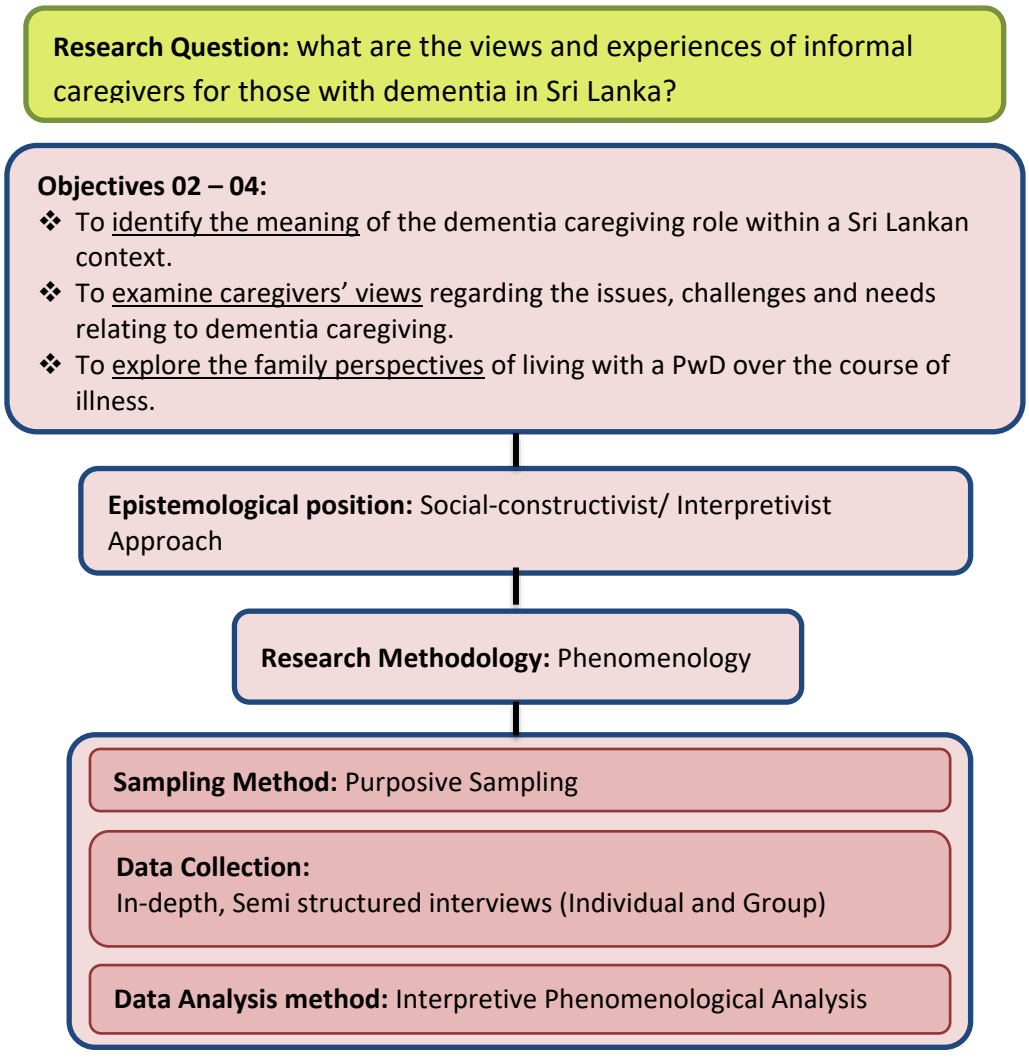

Figure 4.1: Research question, objectives and the overall study design

4.2.1 Target population and study setting

The target population for the study was individuals who care for a person with dementia (PwD) in an informal setting, and were located in the district of Colombo, Western Province - Sri Lanka. Colombo is an urban city which has the highest population (2,309,809) and highest population density (3,300/km^2) of any city in Sri Lanka. This constitutes 11.4% of the total population (Census, 2012). The district of Colombo is divided into 13 Divisional Secretary's Division (DSDs), each headed by a Divisional Secretary. The DSDs are further sub-divided into 566 Grama Niladhari Divisions (GN Divisions). Colombo is a multi-ethnic city composed of Sinhala (74.9%), Moors (9.3%), Tamils (15.3%), Burghers, Malays and others (0.5%). Based on the religion there are Buddhists (70.1%), Muslims (9.7%), Christians (7.6%) and Hindus (12.6%) (Census, 2012; Central Bank of Sri Lanka, 2018).

The study was set at the Kaduwela divisional secretariat division (DSD) situated in Colombo with a population over 250,000. The elderly community over the age of 60 years in this area exceeds 35,000 (DHS, 2016). The Kaduwela DSD consists of 57 GN divisions. Kaduwela is a multi-ethnic area composed of Sinhala (majority), Tamils, Muslims, Burghers, and Malays.

4.2.2 Ethics approval

Prior commencing the data collection (See Appendices 3-B and 4) ethical approval was obtained from the Ethical Review Committee (ERC) of Keele University, UK (Ref: ERP2307) and also from Faculty of Medicine, Kotelawala Defence University, Sri Lanka (Ref: RP/2017/06).

4.2.3 Study participants

4.2.3.1 Sampling method and sample size

Purposive sampling (also called judgment sampling), is the identification and deliberate selection of study participants with particular characteristics that are proficient and well-informed in relation to the phenomenon of interest and are suitable for addressing the aims of the research (Schwandt, 2000; Braun and Clarke, 2013; Etikan, Musa and Alkassim, 2016). Accordingly, a group of informal caregivers (included family members or relatives) who had had experience in providing home-based care for older persons with dementia were purposefully selected.

When using phenomenological approach data is usually obtained from a purposive, homogenous sample, i.e. with similar characteristics (Ali and Bokharey, 2015; Smith, 2017). In some respects, the participants had similar characteristics (in line with a traditional phenomenological approach). However, the sample was heterogeneous in terms of duration of caregiving as well as the PwD's severity of dementia as I wanted a broader range for exploring caregivers' lived experiences as a journey from the onset of dementia to the end-stage or death of the PwD because the sample consisted of participants who cared for PwD in variety of severity levels.

Smith *et al*. (2009) suggest small sample sizes are acceptable for studies based on IPA, but indicate that the appropriate sample size depends on several factors specific to the study. When purposive samples are used, six to twleve in-depth interviews are sufficient to identify patterns in phenomenological studies (Smith, Flowers and Larkin, 2009). Morse, (2000) states that sample size depends upon the scope of the research question, research topic, the study design and quality of data gathered. The purpose in my thesis was to have a broader range (in terms of duration of caregiving and severety

of dementia) in order to collect rich and in-depth information to acquire an insight into participants' views and perceptions (Smith, Flowers and Larkin, 2009). However, the sample size was not pre-determined (Sim *et al.*, 2018), instead data collection was continued until it was judged that data saturation has been reached (See Section 4.2.9). Accordingly, I interviewed 20 families (See Figure 5.1 in page 145 and Table 5.2 in page 149 for more details). This was fairly a large sample which also presented challenges for data analysis (will describe in Section 4.2.8.2, page 131).

4.2.3.2 Inclusion and Exclusion

Two types of interviews were planned: (1) individual interviews with the identified main caregiver (i.e., the person who is involved in most of the care or spends the most time with the PwD), and (2) group interviews with the family members. This therefore, created two sets of inclusion criteria. Inclusion criteria for the individual interview was that the main caregiver was 18 years or over, and able to speak or understand Sinhala or English. Any other family members who were involved in care for the PwD (e.g. wider family or relatives) were invited to participate in group interviews. Minors above age 12 and PwD were not excluded from the group interviews. It was considered that the "family environment" would act as a buffer to any potential vulnerability, and exclusion of these individuals may be more harmful in this context (i.e. removal from a family event may cause distress). However, as suggested by the local ethics committee in Sri Lanka, minors under 12 were excluded from the group interviews as they might be distracting to the interview and may not understand the content of the interview. The interviews were arranged during the day time when the minors were away from home, attending day care or school to avoid their involvement in group interviews.

4.2.4 Preparation of study documents

Developing the interview topic guide

A topic guide contains a prepared set of questions and topic areas to be covered in the interview (DiCicco-Bloom and Crabtree, 2006; Silverman 2013). Topic guides help the researchers to think of possible areas that are important to cover in interviews in order to address the research question (Smith and Osborn, 2003). Two topic guides were developed to facilitate the interviews: (1) for main caregiver interviews and (2) for group family interviews (See Appendices 5 and 6). Both included open-ended questions that flow logically and cluster in topic-based sections (Braun and Clarke, 2013). Opening questions in the topic guides were less probing and closing questions were more sensitive and open. I also used prompts and probing (such as 'Could you tell me/ explain a little more about that?', 'What makes you say so?') to encourage the participants to open up and expand on their responses in more detail (Braun & Clarke 2013, p 81-85).

Both of the topic guides included questions and prompts related to the study participants' background information (e.g. age, relationship to the PwD, and demographic information such as occupation and level of education), challenges in relation to caregiving or potential support needs and suggestions to overcome the possible challenges. The topic guide for individual interviews included further questions and prompts related to the main caregiver's role (experience and perceptions towards their role as the main caregiver). The topic guide for group interviews included more questions and prompts related to family perspectives towards dementia such as their experience when they first learned about their relative

having dementia, responses as a family and their perception of caregiving, and each family member's role in providing care.

These topic guides allowed me to be focused on the aims of the research (Smith and Osborn, 2008); however, in line with the semi-structured interview approach (described below in Section 4.2.6), these were not adhered to rigidly, but were instead used flexibly in order to allow for exploration of unexpected findings or other aspects of experience that may be salient to the participants during the interviews. Use of the topic guides also minimised the chances of repeating questions, thus allowing a smooth flow of conversation, whilst not constraining or limiting the participants' opportunity to express their ideas.

Translating the documents to Sinhala

All the documents required for participant recruitment and data collection were initially prepared in English and then translated to Sinhala; the native and familiar language of the participants. The documents translated were: the invitation letter, information leaflet, confirmation letter, consent forms and the interview topic guides (See Appendices 5 to 12).

When using research documents across different cultural groups, these need to be translated appropriately, and also to be adapted culturally in order to maintain the content validity, internal consistency and reliability across different cultures (Beaton *et al.*, 2007). Beaton *et al.* (2007) suggested a six stage process that includes: Translation, Synthesis, Back Translation, Expert Committee Review, Pretesting and Submission, and Appraisal. The term 'cross-cultural adaptation' refers to a process which looks at both language (translation) and cultural adaptation issues in the process of preparing study instruments to be used in a different setting (Sumathipala

and Murray, 2000). Sumathipala and Murray, (2000) suggest a group method as opposed to individual translation and back translation, and recommend it as a more efficient way to translate or modify a research instrument as it minimises the drawbacks of back translating the contents. They argue that a group method 'eliminates inadequate or ambiguous terms and generates culturally appropriate translation' rather than one or more individuals making decisions arbitrarily and handling the translations and back translations (Sumathipala and Murray, 2000). In light of these advantages, I used this group method when translating the study documents into Sinhala.

As suggested by Sumathipala and Murray, (2000) the group for the translating process should be selected to ensure subject expertise and be representative of the target population. Group members need to be aware of the objectives of the materials to be translated and be familiar with the concepts involved in order to offer more reliable adaptation (Del Greco, Walop and Eastridge, 1987; Sumathipala and Murray, 2000). The group included seven members fluent in both English and Sinhala languages. The group consisted of medical and health professionals, persons with non-medical background, and experts in Sinhala language, ethics, public health and qualitative research methods. A lay person without a higher academic background was also included in the group. The translation process was carried out at Institute for Research and Development (IRD), Sri Lanka. I led the group and moderated group discussions throughout. The procedure was as follows:

- Initial Sinhala translation of the documents was done by me. Each participant was provided with a copy of the Sinhala translation and the original English version in advance of the meeting.

- On the day of discussion, I presented the translation section by section and the group discussed their opinion towards the appropriateness of the sentences.
- Participants were asked to read the translation and decide whether the Sinhala translation represented the idea conveyed by the English version. Sumathipala and Murray, (2000) have shown that linguistic equivalence is less important than conceptual and semantic equivalence; therefore, the meaning conveyed by each sentence or paragraph was focused upon rather than a direct word-to-word translation.
- Each member of the group recorded their observations individually. They were asked to decide whether the sentences or the paragraphs were appropriate, inappropriate or if necessary, suggest new sentences to give a better meaning. No discussion took place in this stage and the group did not compare their opinion with others.
- The group suggested the adjustments or amendments accordingly.
- All the suggestions were recorded and discussed. Translations that achieved consensus as appropriate were included and inappropriate sentences were dropped.
- The most appropriate translation was agreed by the group during the discussion and selected as the final version.

4.2.5 Participant recruitment

4.2.5.1 The dementia clinic

A dementia clinic at the National Hospital Sri Lanka (NHSL) was conducted every Monday afternoon under the supervision of a consultant psychiatrist. This clinic staff consisted of a group of psychiatrists, nurses and community social workers. Patients

were referred to this clinic mainly from the National Institute for Mental Health (NIMH) Sri Lanka, and the other base hospitals and peripheral hospitals in Colombo.

About twenty to thirty patients attended the clinic per day, with four to five new registrations each day. During their first visit to the clinic, patients were assessed and diagnosed for dementia by a psychiatrist. After the first visit there was a compulsory second visit within two weeks. Thereafter, PwD were given the dates for subsequent monthly follow-up visits; family members visited these follow-up clinics with or without the PwD. The purpose of these follow-up visits was to monitor progress of illness, update the medical prescriptions and issue medication to the PwD. Some of the medications were issued free of charge from the hospital pharmacy; the family members were instructed to buy the rest from outdoor pharmacies which are private and external to the hospital.

4.2.5.2 Recruitment Process

A sample of informal caregivers of PwD who were registered at the NHSL dementia clinic and who resided in Kaduwela DSD during the study period were invited to take part in the study. In order to recruit participants, I visited the aforementioned dementia clinic in NHSL, Colombo over a period of four months starting from 19th June 2017. Permission to access the dementia clinic, PwD records and clinic attendance register was obtained from the consultant psychiatrist at the clinic. If PwD was from the selected study setting (Kaduwela DSD) they were considered as potentially eligible. I accessed the clinic attendance register and PwD records in order to (a) confirm the diagnosis of dementia, (b) to obtain the medical history of the illness, and (c) to obtain the contact details (caregiver's name, address and phone numbers) of those who did

not attend the clinic during my presence. Potential participants (those who fulfil the inclusion criteria) were then contacted and invited to take part in the study.

A dual recruitment process was used. The potential participants who attended the clinic when I was present were contacted directly, and contact details for the rest of the potential participants (who were already registered, but currently not attending the clinic) were obtained from the clinic attendance register and then contacted by phone.

The main caregivers or family members visited the clinic either with or without the PwD; I met them after the consultation with the psychiatrist. After about ten minutes explaining the purpose of the study and my role, the invitation letter (See Appendix 7, page 407 and the information leaflet (See Appendix 8, page 408) were given to the potential participants. During this time the contact details (including name, postal address and telephone number) of the main caregiver (or the family member who visited the clinic) was confirmed and verbal permission was obtained to contact them later and arrange a date for interview if they were willing to consider taking part in the study.

Information obtained from the clinic attendance register was used in order to contact the caregivers (by phone) who were not attending the clinic. The clinic attendance register included information about the PwD (such as name, gender, age, date registered, clinic ID), and the contact details of the caregiver (name, address and contact number of the caregiver) from year 2015 onwards. The invitation letters and the information leaflets were posted to those who expressed an interest in taking part in the study.

The information leaflet described the purpose of the study, an explanation that their participation in the research was voluntary, as well as an explanation regarding anonymity, and the risks and benefits of participation. Participant recruitment was carried out over a period of four months during which time the data collection was also initiated simultaneously. Participants were given time (usually 2 – 3 days) to read and understand the information leaflet, and also to discuss among family members before they decided to take part in the study.

Those who were invited to participate were contacted by phone to ensure that they had received the invitation and read the information leaflet. If the potential participants wished to receive more information they were able to ask questions and clarify their concerns during the phone conversation. When the potential participants confirmed their willingness to take part in the study, a mutually convenient date and time was arranged for the interview to take place. A confirmation letter was sent to the participants, which was addressed to the main contact person (See appendix 12, page 417). Participants were given the opportunity to decide whether they were going to take part in either the individual interview, the group interview or both. The main contact person was asked to discuss this with the rest of the family members and convey their willingness to me. Potential participants included family members (including minors over age 12), friends, relatives or neighbours who were involved in caregiving. Figure 4.2 illustrates the participant recruitment process.

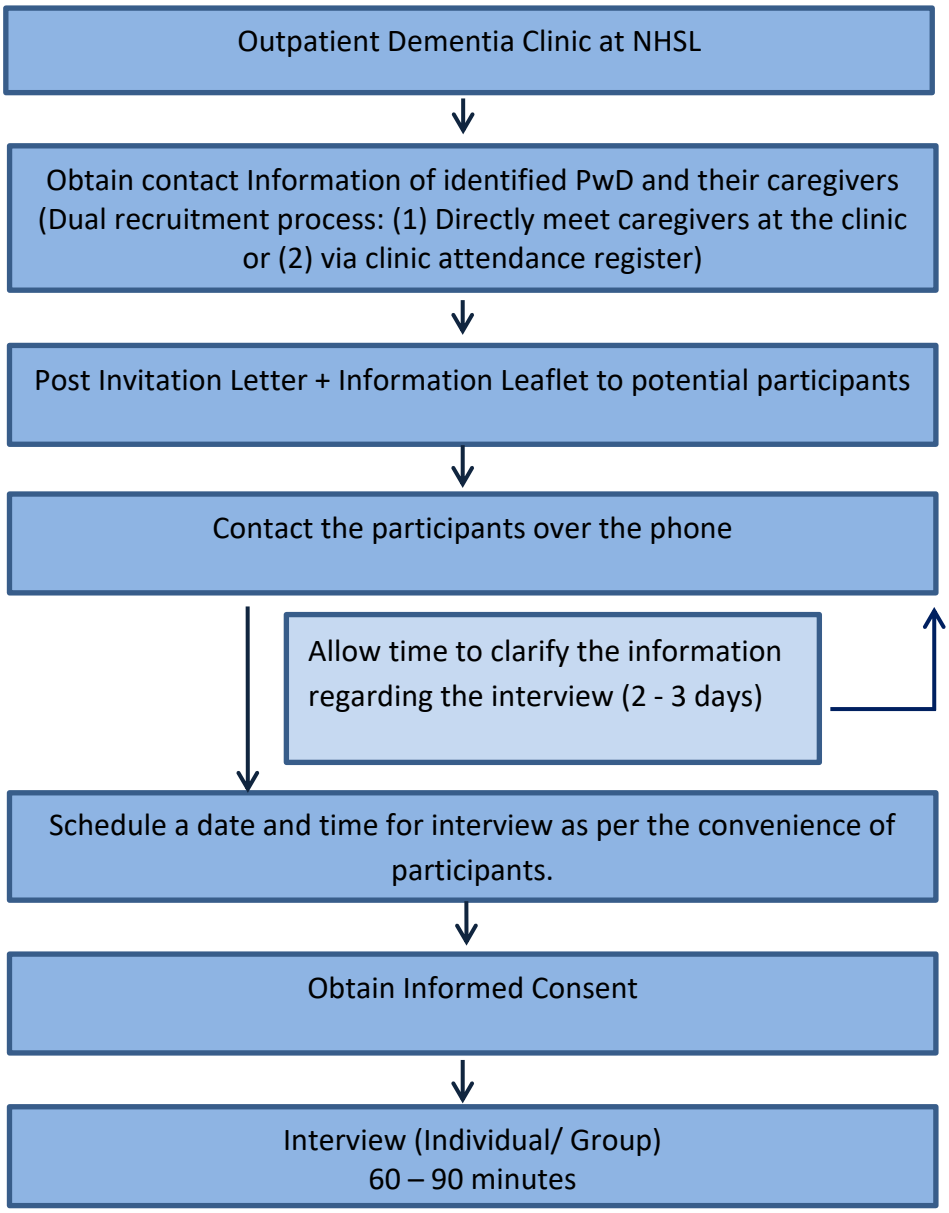

Figure 4.2: Flow diagram of participant recruitment process

4.2.6 Data collection

4.2.6.1 Interviews

Braun and Clarke, (2013) define the process of interviewing as 'a professional conversation', with the goal of getting a participant to talk about their experiences and perspectives, and to capture their views and concepts in relation to a determined topic. Interviews have the potential to elicit 'rich descriptions' (Bloomberg and Volpe, 2017) and therefore are suitable for 'experience-type' research questions and arguably the

best method to explore the participants' understanding, perceptions and personal experiences (DiCicco-Bloom and Crabtree, 2006). In order to construct the meaning of a situation, open-ended questioning is considered to be the best method as the researchers can listen carefully to what people say, discuss and clarify statements and probe for additional information (Ali and Bokharey, 2015).

Bloomberg & Volpe (2017) suggest that the data collection method should be chosen in order to gather the required information in the most appropriate and meaningful ways, and must be congruent with the philosophical and methodological underpinnings of the research. The current study required engagement with the family caregivers in their actual caregiving settings in order to understand the essence of the caregiving experience and the meaning of their experiences as described in their own words. Therefore, in accordance with the chosen phenomenological approach, semi structured, in-depth interviews guided by the two aforementioned topic guides (see Appendices 5 and 6) were used as the primary method for data collection (Ali and Bokharey, 2015; Meyer, Cullough and Berggren, 2016). A phenomenological approach usually employs one-to-one interviews because it focuses on the life experiences of the individual and how they construct meaning (Morse, 1987; Larkin, Watts and Clifton, 2006; Bevan, 2014). Individual, in-depth interviews allow the researcher to capture a person's perspective regarding an event or an experience (Creswell, 2013; Bloomberg and Volpe, 2017), and to delve deeply into social and personal matters, whereas group interviews allow the researcher to obtain a wider range of experience. Accordingly, in-depth, individual interviews with main caregivers were useful to elicit clear pictures from the main caregivers' perspectives and obtain deeper understandings on their role as a main caregiver (Ali and Bokharey, 2015). These allowed the main caregivers

to open up freely and explain their thoughts, feelings and emotions during these one to one interviews. Semi-structured interviews also allowed me a degree of freedom to probe any interesting or unexpected issues relevant to the research that arose during the conversation.

I also conducted group interviews as an interpretivist approach encourages knowledge generation through human interactions and shared construction of meaning (Sandberg, 2005; Avenier and Thomas, 2015). Sandberg (2005) writes that the shared meaning constitutes the 'intersubjective reality' among members of a group who have been interacting over time. The purpose of the group interviews was to understand the family dynamics of dementia caregiving, to capture a range of diverse responses and to explore different perspectives held by individual family members. During the group interviews the participants disputed, agreed upon or negotiated the responses, and these discussions were constructive (DiCicco-Bloom and Crabtree, 2006; Meyer, Cullough and Berggren, 2016). Group interviews were important for me to understand the diversity of individual and family perspectives towards dementia, construction of meaning and experiences shared within the family unit, and also the different caregiving roles played by the family members. In most of the cases group interviews were helpful for the study participants to increase dementia awareness and to understand each other's concerns towards caregiving (I will discuss the outcomes including advantages and disadvantages of group interviews later in Chapter Seven, Section 7.4, Chapter Eight, Section 8.3.1 and Chapter Nine, Section 9.6).

All interviews were conducted face-to-face. Novick (2008) proposes that face-to-face contact is the 'gold standard' and the ideal way to conduct interviews as it allows the interviewer to pick up on non-verbal responses and visual cues, as well as developing

a stronger rapport and to further clarify interpretation of responses. Face-to-face interviews were helpful for me to discuss more sensitive areas such as issues, challenges and psychological aspects of caregiving.

4.2.6.2 The Zarit caregiver burden interview (ZBI)

A pre-tested and validated Sinhala version of the *Zarit caregiver burden interview (ZBI)* was used to provide additional context to supplement interviews by assessing the potential caregiver burden among the study participants (See Appendix 13, page 418). ZBI is a widely-used self-report measure to assess caregiver burden (Miyamoto, Tachimori and Ito, 2010; Flynn Longmire and Knight, 2011). All the participants (both main caregivers and family members) were asked to complete the ZBI questionnaire at the end of interviews (both individual and group) to avoid it influencing their responses during the interview.

The ZBI is a self-report questionnaire which uses a Likert scoring scale that includes 22 items to measure caregiver burden. Twenty-one items measure several domains of caregiver burden whereas the 22nd item is a global measure of caregiver burden (that is "Overall, how burdened do you feel in caring for your relative?"). The items are used to assess personal strains including caregivers' negative feelings (e.g. anger, frustration), role strains (e.g. self-criticism) and social strains (e.g. stigma, isolation) including dependency of PwD, and the effect caregiving has had on the caregivers' health and well-being as well as their relationships with others (Flynn Longmire and Knight, 2011; Oh and Kim, 2017). Each item on the ZBI is a statement which the caregiver is asked to rate using a 5-point scale. Response options range from 0 (Never) to 4 (Nearly Always) (Zarit, *et al*., 1980; Zarit, *et al*., 1986). This measure has been translated into Sinhala by the IRD and pre tested and validated in the Sri Lankan

context (Abeywickrema, Weerasundera and Ranasinghe, 2015). Measures obtained through the ZBI questionnaire were compared with the findings that emerged from the in-depth interviews.

4.2.6.3 Informed consent

The participation of all participants was voluntary and with written informed consent, assent or consent (by proxy) (See Appendices 9-11). Written informed consent was obtained, witnessed and counter signed immediately prior to interviews taking place from all the adult participants on the day the interview was conducted. During the consent process, participants were given a further opportunity to ask questions about the project, and key information was repeated. When children were also present in group interviews, informed assent was obtained from their parents or guardian prior to the interview. On a few occasions the PwD also participated in the group interviews. In such situations the consent was obtained by proxy from the main caregiver or the family member who is the guardian of the PwD as I did not assess their capacity to consent.

Participants were informed of their right to withdraw from the study before or during the interview and in the case of individual interviews, up to one month after the interview date. However, in the case of group interviews, it was made clear to participants that if they choose to withdraw from the study, it is not possible to remove their contributions from the analysis, as removing the contribution of one person from a group interview may significantly alter the meanings within the data. Participants in group interviews could, however, request that their own data not be included as quotations in research outputs (including the thesis or any publications). Informed consent was checked again after each interview by asking the participants whether

they have any concerns or need to alter their decisions regarding the signed consent form. None of the participants asked to withdraw from the study.

4.2.6.4 Conduct of individual and group interviews

The semi-structured interviews started with few general questions in order to collect demographic information about each participant. That helped me to build rapport with the family members especially the ones I had not met before at the dementia clinic. The interviews were conducted in Sinhala as this was the everyday language of the participants. The interviews ranged from 45 minutes to 90 minutes in duration. The majority of the interviews were around 60 minutes in length. All interviews were conducted by me using the topic guides; however, the interviews were mostly participant led and carried out flexibly to allow for more in-depth discussions and probing. Yeo *et al.*, (2014) state probing is necessary until the researcher feels they have fully understood the participant's perspectives. Four junior colleagues shadowed four of the group interviews with the permission of the study participants (one person at a time). I introduced them to the family members before commencing the discussion and the purpose of their shadowing was clearly explained (i.e., training or building their interviewing skills and contribution as note takers). The junior colleagues who shadowed the interviews were either interns or research associates at the IRD and were aware of the need to ensure that the information received was treated as confidential. Family members considered them as members of the research team, and therefore, did not hesitate to discuss their concerns in front of them so their presence neither affected the rapport building process nor the quality of the interviews.

All the interviews were audio-recorded on a digital recording device. The recordings were transferred to a secure encrypted laptop and an encrypted USB storage device at the earliest opportunity.

Some families agreed to take part only in the main caregiver interviews and some only the group interviews. In most cases the participants preferred joining both. In such situations the main caregiver interview was conducted first and then followed by a wider discussion with the family at the convenience of family members. The group interviews were conducted in a flexible way so that the participants could also discuss issues among themselves and give their own opinions in relation to the matters explored. The family members were given an opportunity to share their personal views, discuss their concerns of care, contribution to caregiving from the point of view of each other and experience of living with the PwD. Individual interviews, supplemented by group interviews also enabled me to explore their views on how family members can support each other to fulfil caregiving roles. The interviews were ended on a positive note by providing information or psychological support if it was felt that this was needed (e.g. if the caregivers requested such support or if they became emotional). The participants were informed that they could contact me if they wished to discuss any issue further (e.g. concerns arising after interviews). I will reflect this more in the discussion (See Chapter Nine, Section 9.6).

In line with a social-constructionist perspective, the interviews were mostly jointly constructed, contextually contingent events. Selected intersubjective epistemology indicates that the knowledge is co-constructed thus highlighting an interpretivist and constructivist paradigm underpinning interpretive knowledge production whilst seeking an insider perspective (Sandberg, 2005; Avenier and Thomas, 2015). I

recognise the importance of reflecting upon my role in the research process, issues and challenges associated with subjectivity in this work in order to minimise the potential bias and increase trustworthiness (See Section 4.3). Kingdon (2005) and Finlay (2015) argue that the interviewer plays an active role in the interview and therefore, should reflect on how their practices and values may have shaped the data collected. I maintained a reflective diary throughout the data collection and these field notes were used to inform the data analysis (by noting the interpretative components) and also when reporting the findings.

Some of the participants experienced discomfort or psychological distress during the discussions since interviews examined sensitive topics such as caregiver burden. If the interviews brought up such concerns the participants were given opportunity to discuss them with the interviewer and the matters were addressed with empathy and support. The interviewer provided guidance and relevant health information to family caregivers as requested by them. It was noted that one main caregiver may have mild depression and with her consent she was referred to a consultant psychiatrist (I will discuss more reflections related to these in Chapter 9, Section 9.6).

4.2.6.5 Transcribing and translating of the interviews

I scheduled my interviews giving adequate time to transcribe them verbatim after conducting each interview. On two occasions two interviews were conducted on the same day when families agreed to do both individual and main caregiver interviews. Interviews were easier to transcribe when they were fresh in my mind and I could recall the incidents to reflect on them (Finlay, 2015). Carrying out this process at an early stage of data collection enabled me to understand the areas which needed more

exploration and interview questions were adjusted accordingly before the next interview.

A large volume of data was collected from each interview. All audio recordings obtained from individual and group interviews were transcribed in Sinhala. In order to maintain the clarity and consistency of the transcription the following notations were used as per the transcription notation system described by Braun and Clarke, (2013, p. 165 -167).

- … - long pause
- […] - removed some contents
- [a doctor] - content interpreted by the researcher

The observations and reflections about the interview experience that I recorded in my reflective notebook were also added to the transcriptions. A researcher's reflections on the data collection process and participant's responses can influence the next interviews and the data analysis (Seers, 2012; Finlay, 2015).

Since all interviews were conducted in Sinhala; five selected transcripts were translated to English. The purpose of English translations was to cross check the emerging super-ordinate themes, themes and sub-themes with the research team. Figure 4.3 illustrates the transcribing and translating process.

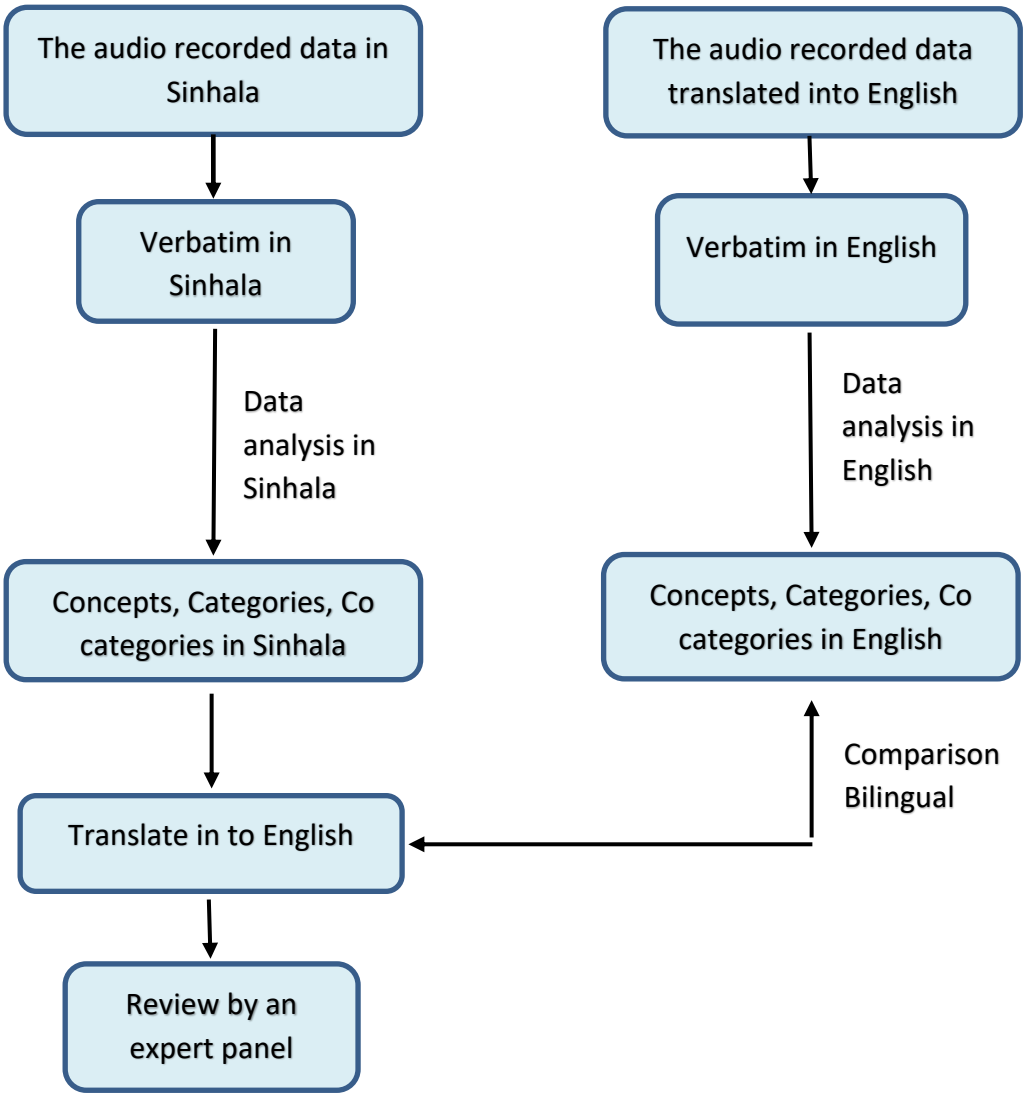

Figure 4.3: The method of translating and transcribing the verbatim

Conducting all the interviews, transcribing and translations were done by myself. This exercise facilitated the data analysis greatly as I could be familiar and immersed in data before starting the analysis. It also facilitated my interpretations. Further reflections including challenges experienced during data collection will be discussed in Chapter Nine, Section 9.6.

4.2.7 Anonymising interview data

Anonymising is a process of changing any information which could potentially identify study participants, including their names, places, religious or cultural backgrounds or occupation (Saunders, Kitzinger and Kitzinger, 2015). When presenting the findings of the current study I have used pseudonyms instead the actual names of study participants. I also avoided naming the places such as hometowns of the participants and institutions involved. There are sensitive data extracts in the results chapters that include narratives which describe difficult aspects of caregiving such as caregiver burden, negligence of care, caregiver abuse or elder abuse in some cases. I avoided using the pseudonyms in such descriptions instead used only the relationship to the PwD (for example 'Daughter: Main caregiver') and I was careful to use such transcript extracts only when necessary to explain the interpretations (Saunders, Kitzinger and Kitzinger, 2015).

However, the cultural and religious views of the study participants are crucial determinants of the findings of this study. Therefore, identity of certain sociocultural and religious values held by the participants was retained in the quotations as they enable deeper understanding of the findings. I will also retain the identity of family relationships such as son, daughter, spouse, and their caregiving role as main caregiver, family member or relative. Instead of the word 'patient' I have used the phrases such as 'older adult' or 'person' with dementia to avoid discrimination and labelling them. The occupations will be described using general terms such as entrepreneur or health care professional.

4.2.8 Data analysis

Data analysis was an on-going, intuitive process which involved continual reflection on the findings (Bloomberg and Volpe, 2017). Analytical approaches are underpinned by specific conceptual and philosophical assumptions of selected qualitative traditions, the methodology and aim of the research (Schutt and Chambliss, 2013). In this thesis the IPA method was used in the data analysis process in accordance with my phenomenological methodology.

4.2.8.1 Rationale for using IPA in the current study

As mentioned in page 111, IPA is considered as the most suitable method to understand the lived experiences of the caregivers, in their own voice, in their own socio-cultural context. In contrast to thematic analysis, IPA concentrates on specific individuals (idiographic approach) as they deal with particular situations or events in their lives; the experience of caregiving for an individual with dementia in the case of current study (Larkin, Watts and Clifton, 2006; Smith and Osborn, 2008), therefore can be used to identify recurrent ideas and concepts within individuals' accounts as well as analysis across the cases (Larkin, Watts and Clifton, 2006). Whilst I was interested in the individual and the uniqueness of experiences, I was also interested in comparing and contrasting experiences and looking for similarities across different caregivers. This was useful to conceptualise aspects of the individual experiences (or shared construction of experience in the case of group interviews) of the caregivers. The IPA seeks 'deeper meanings beyond the manifest account provided by the participants in relation to a wider socio-cultural and perhaps a theoretical context' (an insider's perspective) (Harper, 2012). IPA involves a highly intensive and detailed analysis of the verbatim accounts, the claims are expressed in its own terms rather than

predefined themes (Smith, Larkin and Flowers, 2009; Smith, 2017). Therefore, the IPA method allowed me to look for patterns of meaning and lived experiences of informal caregivers within and across the data accounts and to interpret the essence of those meanings and lived experiences.

Smith and Osborn, (2003) stated that IPA is appropriate where the topic under investigation is novel, or under-researched, or where the phenomenon is complex or ambiguous. The systematic review (Chapter Three) revealed the dearth of evidence-based knowledge regarding informal caregiving for dementia in Sri Lanka.

4.2.8.2 Working with a large sample

Evidence suggests that a small sample size is sufficient for a good IPA study in order to produce a detailed analysis and to describe the patterns for each case and then examine the entire data set to elicit themes across the cases (Smith *et al.,* 2009, page 106). As aforementioned (page 109), I collected large amount of data from lengthy and in-depth interviews. As I had a sample (n=20) which is larger than average for an IPA study this was more of a challenge. Making sense of large amount of data by reducing raw data, identifying what is significant and communicating the essence of findings are the challenges of using IPA (Bloomberg & Volpe 2017, page 233). However, I identified the emergent themes from each transcript (themes within a case), but held off the search for patterns and connections among themes until I completed the data analysis and examined all cases together (cases within a theme). The analysis was primarily at the group level but in accordance with the IPA method I illustrated the group level themes with particular examples taken from individual participants using an idiographic approach (Smith, Flowers and Larkin, 2009). Smith *et al.* (2009) suggested to measure recurrence of patterns across cases for large samples in order to enhance

the validity of the findings. Accordingly, in most of the cases the emergent super-ordinate themes, themes or sub-themes were classified as recurrent if the particular perspectives were present in most of the participant interviews. As a result of the large sample size the overall emphasis shifted towards assessing the key emergent themes for the whole data set (Smith, Flowers and Larkin, 2009).

4.2.8.3 The process of data analysis

The interview transcripts were analysed in accordance with the following steps using an inductive, iterative and multi-directional approach (Smith and Osborn, 2008) which allowed understanding and interpretations of caregiving phenomenon; what it is like from the point of view of the participants:

- Data analysis started with reading through the first transcript to gain understanding and to become familiar with the material.
- A narrative description was first developed through looking at the entirety of the interview.
- The transcript was read again, searching for meaning units (that is, codes) that emerged within that particular case.
- Each meaning unit was labelled to reflect the aspects of the phenomenon it represented, and to capture its essence at an individual level (sub-themes).
- I looked for connections between the sub-themes which emerged and developed 'themes' for the first case. I followed the above steps for other transcripts one by one, and used the analysis of the first case as a guide when labelling the meaning units which I also looked for new themes.
- Then I looked for patterns between the cases, looked for connections between the emerged sub-themes and themes with the aim of establishing 'super-

ordinate themes' (a broader theme that cluster several themes) for each and every case.

- ❖ Further patterns, connections and links were searched across the cases, clustering some of the themes together establishing 'super-ordinate themes'.
- ❖ I developed a table of themes to illustrate the emerged super-ordinate themes, themes and sub-themes across the cases (See Table 9.1, page 285).
- ❖ The essence of these key findings was presented as short quotations in final write-up with examples from verbatim extracts to support each theme in order to communicate experiences and viewpoints offered by the family caregivers.

The process of data analysis commenced with the whole interview transcript being read and re-read line-by-line more than once. Initial reading was important for familiarization and to make sense of the data (Elo and Kyngäs, 2008; Seers, 2012). The transcripts were first read by me and another colleague (LD) individually, and then read together. The transcripts were read several times and discussed to obtain an understanding and an impression of the data (Meyer, Cullough and Berggren, 2016). The junior colleague who shadowed the first interview was asked to analyse the same transcript independently so that I could compare their analysis and annotations with mine. Words and phrases in the text that correspond to the phenomenon (caregiving experience) and encompass key ideas or views, were highlighted and coded during the line-by-line reading using a colour code. Initial impressions of meaning units (codes) were documented in the left margin of the transcript providing preliminary interpretations to them (Smith and Osborn, 2008). These annotations included additional memos or reflections on interesting or significant responses of the participants relevant to the research question and the objectives. As I moved through

the transcripts I noted the similarities, differences, echoes and contradictions of what individual caregivers said, commented on their language, non-verbal expressions and also connections or associations that came to my mind in the left hand margin of the transcript (Smith and Osborn, 2008). Next the codes of this first transcript were discussed with my academic supervisors and different opinions were reconciled before moving to further analysis. Creswell (2013) stated exploration and further clarification of such discrepancies are an important part of the IPA method. Qualitative data analysis involves subjective choices, and it is important to provide a clear audit trail; which means documenting decisions that lead to certain judgements during data analysis, i.e., 'what you have done and why' (Seers, 2012; Bloomberg and Volpe, 2017). The interpretations and reflexivity increase transparency of the analysis process (Larkin, Watts and Clifton, 2006; Smith and Osborn, 2015).

Patterns of data could be identified as I move forward with coding. Some of the codes could merge into a category, which is a cluster of codes that could be grouped together according to conceptual similarities. The identified codes were grouped into sub-themes depending on links between them and a hierarchy was created whereby smaller sub-themes were grouped into bigger themes in relation to each individual transcript (Braun and Clarke, 2013; Meyer, Cullough and Berggren, 2016). Themes described the data in a form which summarises the essence of what being said by each individual participant with a ideographic focus (Larkin, Watts and Clifton, 2006; Smith and Osborn, 2015). Seers (2012) states that themes 'reflect the interpretation of patterns across the data, yet retain the richness, depth and context of the original data'. Sub-themes and themes that emerged were documented in the right margin of the

transcripts. Appendices 14-A and 14-B are examples of analysed transcripts which were translated to English.

This process was repeated for all the transcripts. Following the steps of data analysis rigorously for each separate interview allowed new themes to emerge from each transcript. The analysis was largely inductive, but was also influenced by my research question, objectives and findings from previous literature. The focus of analysis for the individual main caregiver interviews was to understand the individual perspectives of the main caregivers. The group interviews were mainly analysed with a focus of understanding shared meanings and family dynamics. Main caregiver interviews and group interviews were analysed separately and compared with each other to find similarities and differences across the data set. The sub-themes and themes of each transcripts as I came to them were checked with the previously analysed transcripts to make comparisons within cases and across the dataset. Patterns in the emerging themes across the cases were discussed with my academic supervisors and a structure that helped in highlighting converging ideas was produced.

Chen and Boore (2010) stated the meaning of original information can vary when collecting data in one's native language and presenting the findings in another as a result of issues related to translator, translation- back translation process, culture and language resulting negative impact on trustworthiness of the findings. Therefore, data analysis was mainly conducted in Sinhala, the language of the data collection. Selected verbatim extracts were translated to English when presenting examples so that the non-Sinhala speakers can understand the thesis and study participants can have a presence or voice in the final write-up (Osborn and Smith, 2003). However, a few selected transcripts were translated to English as annexures to this thesis (e.g.

Appendices 14-A and 14-B) and to allow for discussion of the data with supervisors. Data analysis was carried out manually using colour pens and adhesive notes as qualitative management software did not support the Sinhala fonts. Colour pens and papers were useful to organise and keep track of my analysis. The quotations to illustrate sub-themes and themes were collected in a table in order to support decisions and arguments during data presentation.

4.2.9 Saturation

In qualitative research saturation is considered as the criterion for discontinuing the data collection and/or analysis based on data-collected to that point (Saunders *et al.*, 2017), and some experts regard this as 'the gold standard' when determine the sample sizes (Guest, Bunce and Johnson, 2006). Saturation can be used when determining when to stop sampling, data collection and data analysis (Guest, Bunce and Johnson, 2006; Briks and Mills, 2015; Saunders *et al.*, 2017).

In the current study I continued participant recruitment and data collection untill similar responses were repeated during the interviews and new data no longer provided additional insights in addressing the research question (Guest, Bunce and Johnson, 2006). After the twelfth main caregiver interview and tenth group interview no new information was heard and the participants responded with similar answers to interview questions. Transcribing and preliminary data analysis (familiarising with data and initial noting) also commenced in parallel to data collection in order to ensure that the data saturation is achieved (Elo and Kyngäs, 2008) and no new meaning units (or codes) appeared in the later transcripts during analysis (Guest, Bunce and Johnson, 2006). Accordingly, after conducting fourteen main caregiver interviews and twelve

group family interviews I was confident that the saturation was achieved and decided to terminate data collection.

4.2.10 Narrative and presenting the findings

Meyer *et al*. (2016) stated the narrative account in IPA approach aim to mix the quotations from participants' own words with interpretative comments as it helps the reader to judge whether the researcher succeeds in representing the perspectives of study participants. In this thesis I presented narrative descriptions relating to each family to provide the context of the phenomenon and the study participants. These also described caregivers' socio-demographic background and the current situation of caregiving (Described in Chapter Five, Section 5.3). However, I used short data extracts and dialogues from group interviews when presenting findings. I have selected the quotations and reported them verbatim that clearly show the ideographic perspectives of the participants, and sometimes the group perspectives of the families. In chapters six to eight the findings are presented according to three super-ordinate themes that emerged and data extracts are drawn-upon to exemplify them.

Researchers own backgrounds shape their interpretation, and they position themselves in the research to acknowledge how their interpretation is informed by their personal, cultural, and historical experiences (Creswell, 2013). Reflexivity is a key part of the phenomenological approach when reporting the findings and evaluating the knowledge generated (Carter and Little, 2007; Smith, Flowers and Larkin, 2009; Ritchie *et al.*, 2014). Taking a reflexive stance enabled me to acknowledge my own subjectivity and analytic choices along with participants' lived experiences that concerns various aspects of caregiving as accurate as possible (as we can never claim to completely understand someone's perspectives or experiences; Ritchie *et al.*, 2014).

4.3 Rigour of the study

Rigour or trustworthiness of a study can be defined as the degree of confidence the researcher has in data, interpretation and methods used to ensure the good quality of the study (Polit and Beck, 2012). It also refers to the degree to which researchers have provided appropriate evidence and explanation to convince the reader. There are several guidelines produced for assessing rigour and trustworthiness of qualitative studies. However, Smith, Larkin and Flowers, (2009) state rigour and trustworthiness of qualitative research should be evaluated flexibly using an appropriate criteria for selected study design. Lincoln & Guba (1985, 1994) proposed five criteria of trustworthiness employed by the researchers who use qualitative methods: credibility, dependability, confirmability, transferability and authenticity. Yardley (2000) presents four broad principles for assessing quality of qualitative research: sensitivity to context, commitment and rigour, transparency and coherence, finally impact and importance. The following is a brief discussion of applicability of these criteria in the current study.

This study demonstrated sensitivity to context since the very moment of the selection of phenomenology as the methodology (Smith, Flowers and Larkin, 2012, p.180 - 185). Inspiration for the research interest on dementia came through my personal experience of being a family member of a PwD. I purposively recruited a group of participants who were providing home-based care for PwD, conducted in-depth semi-structured interviews through close engagement with the participants, the IPA was selected as the method of data analysis as it allowed idiographic approach to explore lived experiences of the caregivers. Socio-cultural sensitivity of the used materials was ensured by translating them into Sinhala and obtaining ethical clearance before using

them in data collection. Sensitivity to context was also demonstrated through participant recruitment, sustained engagement in terms of establishing access and rapport and interactional nature of data collection within the interviews and also through the analysis process (Smith, Flowers and Larkin, 2009). Prolonged engagement with the participants helped to build trust and rapport, which ensures true, rich and detailed responses (Shenton, 2004; Diane, 2014). Rapport and well planned questions were important for generating rich and detailed accounts relevant to the research question (Groenewald, 2004; Cooper, 2010). From every house I visited I received a warm welcome and invitation to revisit them. On some occasions they contacted me later to provide updates, or to seek advice or support for care. I was listening to each and every conversation with an understanding of the situation and empathy, putting the participants at ease and recognising their interactional difficulties. For example, some main caregivers were happy to express ideas when others were not around and, in such cases, interviews were rearranged for when the person being interviewed would be alone. Some family members did not want to participate, so I allowed them to leave the group before commencing the consent process for group interview. Yardley (2017) reports obtaining good data requires interactive skills, dedication and awareness of the interview process.

Analysis and interpretation depends on the analytical intellect, skills, training, capabilities and the style of the researcher (Bloomberg and Volpe, 2017). The researcher's positionality and identity (for example; social, cultural and educational background) influence the data analysis process and trustworthiness. I followed a systematic and organised structure during the entire research process in order to put aside (i.e., bracketing) my personal beliefs and assumptions and to minimise the

incidents that personal views and experiences influence the findings (Meyer, Cullough and Berggren, 2016). Bracketing is important in phenomenology in order to avoid researcher bias and to construct an understanding from the point of view of the research participants, which is often referred to as attempting to gain an 'emic' perspective – an insider's view (Smith, Flowers and Larkin, 2012). I was careful to bracket my childhood experience of living with my uncle who had dementia and my experience as a mental health nurse to understand participants' experiences during the data collection and data analysis. However, it was challenging to try and think like an outsider as it was difficult to completely forget the memories and personal experience of living with a PwD. As a Buddhist I was familiar with some of the concepts, beliefs and practices described by the participants.

Researcher strategies such as peer-debriefing can be used to enhance the credibility and dependability of a qualitative study (Diane, 2014; Connelly, 2016). I asked feedback for my preliminary data analysis from colleagues at the IRD, and my supervisors provided their feedback throughout the data analysis process (Diane, 2014). A workshop 'on raising awareness of dementia care' was conducted after completion of data collection at the NIMH in Sri Lanka in November 2017. Participants who took part in the study were invited to attend this workshop, and the preliminary findings were presented. Twelve main caregivers from the study sample attended this workshop and they agreed with the preliminary themes presented. They also took this as an opportunity to share their experience among each other. Member-checking, (i.e., communicate a summary of the emerged themes and obtain a feedback from participants) is a technique to ensure credibility of qualitative studies (Diane, 2014).

Diane (2014) states that maintenance of an audit trail (collection of materials and notes used in the research process that document important decisions and assumptions) also enhances the trustworthiness of a qualitative study. To see whether the findings were consistent and dependable with the collected data, I maintained a reflective diary with notes of all activities of the research. The diary included details of important decisions made during each milestone of the study, reflections on interviews with observations, notes on non-verbal guesses and hunches, and also my values and feelings during the conversations. Reflexivity is an integral component of IPA method in order to acknowledge values, any pre-conceived ideas or beliefs and experiences held by the researcher which may influence the outcome (Brocki and Wearden, 2006). I have reflected my perspectives throughout this thesis.

The credibility refers to whether the findings are believable from the perspective of the participant, researcher and the readers (Shenton, 2004). The findings of a qualitative study can be deemed credible if they are congruent with the real-life perspectives of the study participants (Shenton, 2004; Creswell, 2013; Bloomberg and Volpe, 2017). However, in general, my familiarity with the context (e.g. Sri Lankan culture and belief systems) helped me to understand caregivers' views and experience of conceptualising dementia and home-based caregiving. I followed an immersive and disciplined attention throughout the data analysis process in order to make sense of participants' views (Yardley, 2000). To demonstrate confirmability of the findings and how the interpretations and conclusions were established, I have used a considerable number of verbatim extracts to support my interpretations and argument being made (Diane, 2014), therefore represented caregivers' voices in the thesis allowing readers to check the interpretations being made (Smith, Flowers and Larkin, 2009).

The current study was not intended to generalise the findings. However, I have explicitly discussed the research context including, Sri Lankan context of dementia, study setting and the procedure for participant recruitment in previous sections. With the thorough description of the study context, location and the participants and being transparent about the analysis process I tried to enhance the transferability of the findings (Connelly, 2016; Bloomberg and Volpe, 2017). The findings were described in detail and discussed in the context of evidence from other Asian contexts as this enabled the findings to be related to similar, but not identical situations. In addition, I have written my reports carefully, making claims appropriate to the sample which has been analysed, and general claims are offered cautiously (Smith, Flowers and Larkin, 2009).

4.4 Ethical considerations

4.4.1 Confidentiality

All confidentiality arrangements adhered to relevant regulations and guidelines (e.g. GDPR and Data Protection Act).

4.4.2 Data storage

Personal data of the participants were stored in a confidential, password protected database accessible by only the research team. Consent forms were kept in a separate location to the research data used for analysis so that no linkage can occur. Hard copies of information were stored in a locked filling cabinet within the IRD's secured data room and scanned images of them were backed up on a secure, electronic, password protected laptop. All of the electronic field data, including all audio-recordings of

interviews and transcripts were stored anonymously to ensure participant confidentiality, and linked to identification numbers only. They were stored on a password protected laptop and backed-up onto an encrypted USB drive.

Following the transfer of the audio-recordings to the encrypted devices, they were deleted from the recording device. Upon completion of the study audiotapes and hard copies of anonymised transcripts (which were printed out to aid initial analysis) will be stored securely in a locked filing cabinet within IRD premises, under the custody of lead supervisor (Prof Athula Sumathipala), in accordance with IRD regulations.

No hard copies of any data or consent forms were carried out of Sri Lanka when I returned to the UK. Instead, scans were made of all documents, and these were transported back to the UK on a password protected laptop and encrypted USB stick. This electronic data will be stored in the UK on the password protected drives within School of Primary, Community & Social Care, Keele University accessible by only the research team. Keele University ethics committee commended the research team for this idea. The panel recommended this idea is shared with the other panels as an example of good practice (See Appendix 3-B, page 402).

After the completion of the study, as a requirement of the School of Primary, Community & Social Care, data will be kept for 10 years. Copies of all electronic data and consent forms will also be stored at the IRD, in accordance with IRD regulations. All the stored data will be destroyed after this time.

4.5 Chapter summary

This chapter described the ontological and epistemological stance adopted in the research, the research design and the methodological approaches of the specific procedures used in conducting the study. The chapter also described the linkages between the research question and research approach, study design and methods selected with justifications for selecting those. The chapter also addressed the issues and strategies related to trustworthiness and ethical concerns of the study. The following chapters will present the findings of this thesis.

Chapter 05

Introduction to the study participants

This chapter presents the descriptive characteristics of the study participants. These characteristics include the key demographic, socio-economic, and health indicators of the main caregivers, family members and the people with dementia (PwD) who participated in the study. In addition, a concise narrative summary of each participating family is provided, including their situation in relation to caregiving. This chapter will enable an understanding of the background and varied characteristics of the study participants as well as the context. The chapter will also facilitate the interpretation of data extracts presented in the later results chapters.

5.1 Background context of study sample

Twenty-six interviews were conducted, including 14 main caregiver interviews and 12 group interviews. In total twenty families were interviewed between June 2017 and March 2018. In eight of these families only the main caregiver interviews were conducted. There were six families who agreed to undertake group interviews only. Six families participated in both types of interviews (See Figure 5.1).

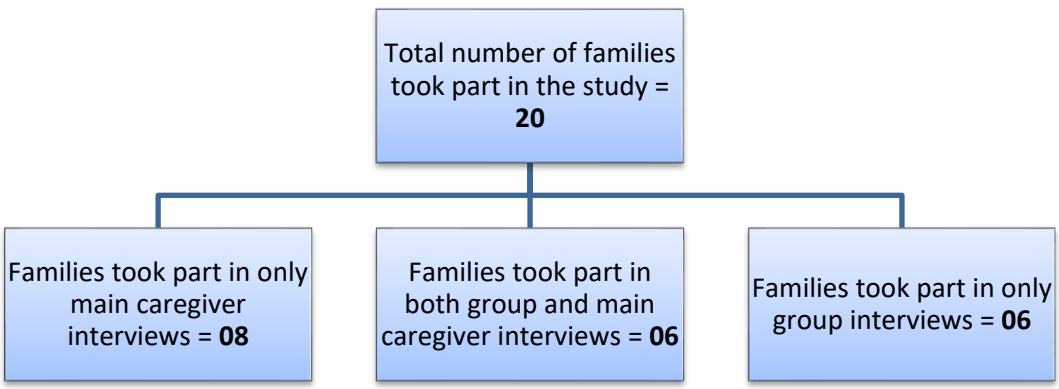

Figure 5.1: The type of interviews and number of families that participated in the study

Twenty-five interviews took place at participants' homes. One individual interview was carried out at the Institute for Research and Development (IRD) at the request of the participant.

Among the contacted families within this study there was one family where the person with dementia (PwD) had passed away, however the family still wished to take part in the study in order to share their experiences. Additionally, one participating family introduced me to another family in which one of the family members was an older person suspected of having dementia, though this was not formally diagnosed and they were not registered with the relevant healthcare services. These families were included in the study as both showed a keen interest in taking part and the participation of a family potentially caring for someone with dementia 'outside' of the current formal care system could potentially add important insights to the data. Detailed information regarding the study setting and participants' recruitment was discussed in Chapter Four, Sections 4.2.1 and 4.2.5.

5.2 Demographic information about study participants

5.2.1 Main caregivers

The majority of the main caregivers who participated in the study were female (n=14, 70%). The age of the main caregivers ranged from 31 to 74, [mean age 57.25 years; SD = 11.75]. The main caregivers were principally (n=12, 60%) the adult children of the PwD (four sons, seven daughters, one daughter-in-law). Other main caregivers were spouses (two wives and a husband), siblings (three sisters, one brother), and one lady who provided care for her former housemaid who had dementia.

In terms of employment and commitment to caregiving, it was found that 60% of the main caregivers were either unemployed, relinquished their employment due to the need for full time engagement in caregiving or retired by the time of data collection. Forty percent of the main caregivers were engaged in caregiving whilst remaining in full-time or part-time employment. Among them were entrepreneurs and professionals. Twenty-five percent of the main caregivers (n=5) shared the caregiving responsibility with another family member to fit around their work hours.

Table 5.1: Socio-demographic characteristics of the main caregivers

Characteristics	N (%)
Age	Mean 57.25, SD=11.75
20 – 39	03 (15)
40 – 59	08 (40)
60 – 79	09 (45)
Gender	
Male	06 (30)
Female	14 (70)
Relationship to the PwD	
Spouse	03 (15)
Daughter	07 (35)
Son	04 (20)
Daughter-in-law	01 (05)
Sibling	04 (20)
Other (looking after former housemaid)	01 (05)
Marital Status	
Married	16 (80)
Unmarried	02 (10)
Widowed	02 (10)
Size of the household	
1 - 4 members	13 (65)
5 - 9 members	07 (35)
Occupation	
Unemployed	07 (35)
Employed	08 (40)
Retired	05 (25)

Ninety percent (n=18) of the main caregivers described their religion as Buddhist, the remainder described themselves as Catholic but married to a Buddhist. The majority (n=16, 80%) of main caregivers lived with the person they care for; only four (20%)

main caregivers lived in a different household. One PwD lived with one of her sons, who did not engage with her care at all; instead her daughters visited her during the day time and attended her caring needs, and a paid caregiver was also hired to be with her during night time. Another son visited his father, who had dementia, daily and attended to his activities of daily living (ADL). In his absence his mother and a relative took over the responsibility of looking after the PwD; especially during the night. It was reported that another PwD was abandoned by her family, and lived on her own by the time of interview as her family refused to keep her with them. One other PwD lived alone as she refused to move in with her son (who is the main caregiver) who lived next door.

5.2.2 People with dementia

The initial contact details of PwD were obtained from the dementia clinic registry (maintained by the clinic) between January, 2015 and April, 2018 (except for the two families mentioned above). Among the recruited families there were 6 male and 14 female PwD, with ages ranging from 62 to 92 years (mean age = 74.5). Except for the family where the PwD had not registered at the clinic, all other PwD had a confirmed diagnosis of dementia after being referred to the dementia clinic at the National Hospital. The family of the person whose dementia was unconfirmed suspected she had developed early symptoms of the disease, and were still awaiting a first clinic appointment at the time of the interview with the main caregiver. As already mentioned, one PwD had already passed away by the time the main caregiver was contacted, however the family were willing to take part in the study. The severity of dementia experienced by the other PwD ranged from mild to moderate to severe or very severe stages of dementia as outlined in Table 5.2.

Table 5.2: Socio-demographic characteristics of the persons with dementia

Characteristics	N (%)
Age	Mean 74.5, SD =9.07
61 – 70	08 (40)
71 – 80	06 (30)
81 and Above	06 (30)
Gender	
Male	06 (30)
Female	14 (70)
Marital Status	
Married	04 (20)
Unmarried	02 (10)
Widowed	14 (70)
Duration of illness (as described by caregivers)	
06 months or less	02 (10)
07 – 18 months	01 (05)
19 – 36 months	08 (40)
37 months and above	05 (25)
Unknown	04 (20)
Most recent clinic visit[#]	
Never	01 (05)
More than six months	09 (45)
1 – 6 months	00 (00)
Less than a month	03 (15)
Only a caregiver attends the clinic monthly (without the PwD)	07 (35)
Severity of dementia*	
No cognitive impairment	00 (-)
Mild	01 (05)
Moderate	03 (15)
Moderately severe	05 (25)
Severe	05 (25)
Very Severe	04 (20)
Passed away in very severe condition	02 (10)

[#] The dementia clinic offers facilities for the caregivers to visit the clinic without the PwD to update their medication prescription and offer some of the medications free of charge; The clinic attendance registers and other records contain information from the date they first visited the clinic.

* According to Global Deterioration Scale criteria described in Chapter 2

Unfortunately, the clinic records provided no details regarding the type of dementia diagnosed in the majority of PwD (80%). For those where the type of dementia was known, there was one person with vascular dementia; three others were diagnosed

with Alzheimer's disease. The caregivers of those who did not have a confirmed diagnosis for type of dementia reported that no further investigations were undertaken to confirm the classification of the disease as they discontinued the clinic visits.

Differences were found in the way the study participants attended the dementia clinic. Forty-five percent of PwD, who had registered at the dementia clinic, were no longer attending the dementia clinic by the time of interview, with only three PwD attending the dementia clinic regularly (See Table 5.2, page 153). Seven families (35%) reported that a family member (not necessarily the main caregiver) usually visited the clinic once per month, but without the PwD. The main reason for this visit was to update the medication prescribed for the PwD.

As mentioned above, not all PwD attended the clinic and many had not attended recently and therefore clinical indications of cognitive severity (measured using the MMSE at clinic) were considered unreliable. For these reasons I administered the GDS at the point of interview to give an indication of cognitive severity (described in Chapter One, Table 1.1, pages 4-5). In terms of the sample, only one person had mild dementia, three persons had moderate dementia, while thirteen had moderately severe to very severe dementia (See Tables 5.2 and 5.3, pages 153, 155).

According to the information gathered via caregivers, 75% of PwD also presented with other medical conditions, such as high blood pressure, diabetes mellitus and osteoarthritis. Conditions such as asthma, epilepsy and vitiligo were also reported. There were two older adults who had other comorbid mental health conditions before being diagnosed with dementia.

Table 5.3: Summary of the selected characteristics of main caregivers and persons with dementia

Main Caregiver *	Age	Gender	Occupation	Relationship to the PwD	Duration of Caregiving in months#	PwD*	Age	Gender	Marital status of the PWD	Possible onset of dementia in months	Level of Cognitive Decline**
Rani	52	F	Housewife	Daughter	24	Mervin	88	M	Widowed	36	Moderately Severe
Kumari	47	F	Housewife	Daughter-in-law	60	Siriyawathi	71	F	Widowed	60	Very Severe
Sriya	66	F	Housewife	Sister	54	Hema	65	F	Widowed	54	Very Severe
Nirosha	31	F	Housewife	Daughter	12	Dharma	65	F	Widowed	unknown	Moderately Severe
Nelum	67	F	Housewife	Sister	12	Sujatha	65	F	Widowed	24	Very Severe
Jinadasa	72	M	Entrepreneur	Husband	24	Malani	70	F	Married	24	Moderate
Sujeewa	55	F	Housewife	Daughter	24	Jane	82	F	Widowed	24	Moderately Severe
Chandrika	60	F	Retired Health care professional	Daughter	24	Kusumawathi	86	F	Widowed	24	Moderately Severe
Kelum	31	M	Entrepreneur	Son	18	Asilin	65	F	Widowed	24	Severe
Saman	48	M	Entrepreneur	Son	60	Amarasiri	70	F	Married	60	Very Severe
Nimala	64	F	Retired professional	Wife	48	Dayasiri	74	M	Married	48	Severe
Niluka	38	F	Housewife	Daughter	24	Siril	78	M	Widowed	15	Very Severe-when passed away
Dinesh	50	M	Entrepreneur	Son	24	Leela	66	F	Widowed	unknown	Moderately Severe
Rose	58	F	Professional	Wife	12	Basil	62	M	Married	6	Moderate
Premasiri	71	M	Retired Professional	Brother	48	Siridasa	72	M	Unmarried	unknown	Very Severe-when passed away
Jayanthi	66	F	Retired Health care professional	Sister	3	Gunawathi	85	F	Widowed	3	Mild
Gayan	56	M	Entrepreneur	Son	6	Saralin	80	F	Widowed	unknown	Severe
Mallika	71	F	Retired Health Care Professional	Daughter	24	Sheela	92	F	Widowed	24	Severe
Soma	71	F	Retired Professional	Former Employer	24	Nimalawathi	71	F	Unmarried	24	Severe
Samanmali	55	F	Entrepreneur	Daughter	48	Rosalin	83	F	Widowed	48	Moderate

*Pseudonyms were used to protect the anonymity of the participants

** The level of cognitive decline is determined according to the criteria given in Global Deterioration Scale (Source: Reisberg et al., 1982). This was described in Chapter One, Section 1.1.3, pages 4-5

#These are approximate figures as described by the caregivers, showing the time duration of caregiving since the PwD first displayed signs of dementia

5.3 Summary of the narratives

Smith *et al.* (2009) suggest presenting a clear, full narrative account of the study participants in phenomenological studies to provide the context of the phenomenon and the study participants. It appeared that each and every person who took part in the interviews had a unique story to tell. Using a phenomenological approach the focus was on comprehending their individual 'world of daily life' (Schütz, 1970); specifically, the way they perceive, understand and describe the experience of living with a PwD or providing care for a PwD based on their beliefs, thoughts, assumptions and attitudes. Meyer *et al.* (2016) states that the focus on the individual's life-world allows the researcher to gain a better understanding of the phenomenon, his or her day-to-day life and the relationship between the individual and the world. Accordingly, I present a narrative for each family in order to describe their socio demographic background and the current situation of caregiving. These narratives provide context for the analysis presented in relation to the four main themes identified in the data, which will be described in next three chapters. The narratives outlined below are provided in the order in which the interviews were carried out. The study participants were anonymised by replacing real names with pseudonyms as described in the Chapter Four, Section 4.2.7.

1. Rani and her father Mervin

Rani, a 52-year-old housewife was my first participant. The first group interview was conducted with Rani and her family members, and later an individual interview was undertaken with her. Rani reported she had been the main caregiver for her 88-year-old father Mervin for two years at the time of interview. Her

husband and the two grown up children live in the same household but were mostly away from home due to work.

Mervin, a father of two sons and four daughters, was previously a successful entrepreneur who lived an independent life. According to Rani, Mervin had started showing early signs and symptoms of dementia about three years ago but the family did not recognise them. Rani reported that all the family members were angry at him for his behaviour and stopped paying attention to him resulting in Mervin becoming homeless as the children had repelled him from their houses. Later, he has been wandered and some nights were spent in the bus halts along the road or in temples without care and attention from anyone. According to Rani, Mervin once went missing for several days. The family was subsequently informed that Mervin had been seen begging on a road-side near his home town and finally the police found him and notified his children.

A relative has suggested seeking medical advice and they had visited a mental hospital about three months prior to the interview. Mervin was diagnosed as having dementia and then referred to the dementia clinic. According to Rani, some of the family disputes created by Mervin's previous behaviours are still not resolved and Rani found it difficult to convince her siblings that Mervin has dementia, even after he was clinically diagnosed. Rani said she volunteered to become the main caregiver as no one else agreed to look after him. Her husband appears not to get involved in taking care of Mervin but is happy for him to stay in their family home. Rani's children and one sister currently support her.

When I met Rani and her family Mervin was on medication, Rani was well aware of dementia and its symptoms and was very keen to keep up with his regular clinic appointments and treatment check-ups.

2. Kumari and her mother-in-law Siriyawathi

Siriyawathi is a mother of three children, a son and two daughters. Forty-seven-year-old Kumari has been living with her mother-in-law since her husband, Siriyawathi's son, passed away. Kumari explained that the two daughters had a conflict over the family property, which resulted in them abandoning their mother as she denied what they requested. It has been about five years since Siriyawathi developed forgetfulness and Kumari became the main caregiver. Kumari is now re-married and the couple live in the same house and care for Siriyawathi as their own mother.

Siriyawathi was also on medication for hypertension, diabetes, arthritis and insomnia when she first showed the behaviour changes. One day Siriyawathi had accidentally overdosed on her sleeping tablets, she was admitted to the hospital, and was unconscious for a few days. She was first diagnosed with dementia during this hospital stay and was referred to the dementia clinic. A year later Kumari gave up her job to look after her mother-in-law as she became more and more dependent and needed more attention.

3. Sriya and her sister Hema

The third main caregiver interviewed was Sriya, a 66-year-old lady providing care for her younger sister, Hema. Sriya has made a promise to her dying mother years before that she would take care of Hema, who also suffers from epilepsy. Sriya has kept her promise, becoming Hema's main caregiver without thinking of her

personal life. Hema is married and has two children, who do not live at home most of the time. Her husband, Sena, is now retired but is still the bread-winner for the entire family.

Hema was diagnosed with dementia which doctors suspect may have developed as a result of her long-term epilepsy. At the time of the interview Hema had severe cognitive decline and had recently developed urinary incontinence. Sena said that she often refuses her meals and medications and demands constant attention. Sriya reported that Hema often wanders around the house whilst experiencing hallucinations and delusions which include talking with her dead parents and an imaginary son. Hema sometimes becomes very aggressive and violent.

It was Sena who made all the decisions about Hema's care arrangements and treatments. Sena represented Hema at the dementia clinic and regularly updates doctors about her condition. Currently Hema receives both medical (western medication) and alternative (traditional and religious) treatments for her condition. Sena reported that the expenses for treatments are unaffordable for him but the relatives provide financial support and transport when necessary.

4. Nirosha and her mother Dharma

Dharma is 65 years old, and diagnosed with a chronic delusional disorder. According to her daughter Nirosha, Dharma and her husband *'did not see eye to eye'* so family conflicts were common in their household. Nirosha has been her mother's main caregiver since her father passed away when she was thirteen years old. Recently Dharma has become forgetful and started wandering. She was clinically diagnosed with dementia about a year prior to the interview but the exact onset of

illness was not known. Nirosha's two older brothers currently live overseas and support her financially to look after their mother.

Dharma's forgetfulness, aggressiveness and wandering behaviour are currently challenging for Nirosha as she is the only person available to look after her. Nirosha has quit her job and become a housewife in order to look after her mother, as well as babysitting her six-year-old daughter. Nirosha currently feels overwhelmed by her caregiving responsibilities and problems related to her mother's illness.

5. Nelum and her sister Sujatha

Sujatha, a 65-year-old widow, has lived alone since her husband passed away. During a family visit her sister, Nelum and brother-in-law, Edwin, have noted her unusual behaviour and sought medical advice as instructed by their son, a qualified doctor. Sujatha was diagnosed with dementia and when Nelum volunteered to become her sister's caregiver, Sujatha moved in with Nelum and Edwin. Unfortunately, as Sujatha has deteriorated rapidly it has been difficult for Nelum to take care of her at home. As both women are old and Nelum is not physically capable of providing the necessary care, Edwin has suggested admitting Sujatha to the mental hospital where he will receive professional help. Nelum said she disagreed at first, but felt she had no choice when things became worse. At present Nelum and Edwin visit the hospital as often as possible to spend time with Sujatha.

6. Jinadasa and his wife Malani

Jinadasa is a 72 years old caregiver for his wife, Malani, who has dementia. He is also diagnosed and receiving treatment for chronic renal disorder. Malani also has diabetes, arthritis and vitiligo and takes medication for all three conditions. She usually self-injects her Insulin. She has recently developed forgetfulness, and her

dementia seems to be gradually worsening. Their daughter wants to take care of her by moving Malani to live with her. However, Jinadasa has insisted that Malani stays with him. Jinadasa said he is not fully aware of her insulin doses or other medicine she takes and lacks the skills to administer them. Neither does he seem to understand her condition, especially why she often forgets things.

Malani said she still remembers most of her daily routine and manages to cook if she has written instructions. Her daughter and relatives find it difficult to manage her care as Jinadasa keeps refusing to consider the idea that she moves in with their daughter. Malani's sister frequently visits to help her with housework, monitor Malani's condition and remind her to take her insulin injections.

7. Sujeewa and her mother Jane

Sujeewa and her husband Lal provide care for 82-year-old Jane, who has dementia. Jane fell and sustained a hip fracture about three years prior to the interview. The hospital nurses at this time first identified Jane's–forgetfulness and BPSD and referred her to a dementia clinic during her stay.

Though the couple have recently built a new house they still live in their old property as Jane gets more agitated when she is in a new environment. Sujeewa and Lal reported they are frustrated by frequent struggles to keep Jane home, control her risky behaviours that may lead to falls, and answering her frequently repeated questions. At the time of interview both were diagnosed with mild depression for which they were-taking medication.

8. Chandrika and her mother Kusumawathi

Chandrika, a 60 years old retired health care professional, is the main caregiver for her mother, Kusumawathi. About two years ago she first noticed her mother's forgetfulness and behaviour changes such as irritability and aggressiveness. Kusumawathi has been a very religious woman who observed at *Sil* on every *Poya* day. Later she has started using abusive words, got angry for minor incidents and become *'a trouble'* to family members. Chandrika said she frequently gets agitated and screams during the night, so other family members were also unable to sleep. Kusumawathi was taken to the mental hospital for treatments and referred to the dementia clinic.

Chandrika explained that Kusumawathi cannot currently recall many recent events, including her daily activities such as mealtimes. She requires assistance with showering and getting dressed but can manage eating and going to the toilet by herself. They have attended the dementia clinic only once, about a year prior to the interview, but had not continued with further tests to confirm the condition due to difficulty in travelling and Kusumawathi's refusal to attend. Currently Kusumawathi is not on any medication for dementia. Both women have Asthma, the only condition for which they take medication.

9. Kelum and his mother Asilin

Kelum is 31-year-old entrepreneur who looks after his mother with the help of his aunt, Suneetha. Suneetha has previously worked as a care assistant in a hospital. Kelum was initially reluctant to accept Asilin's dementia diagnosis but Suneetha has insisted that he see a doctor and initiates medical treatments for his mother; she has even volunteered to become the main caregiver as Kelum needs to work.

Kelum said he recently rebuilt their house according to new astrological guidance but Asilin finds it difficult to remember the recent changes made to her house and she often urinates in her room or the living area. He also explained that she becomes irritable and aggressive when relatives visit her; therefore, no one likes to do so. Kelum has promised his mother that he will stay single and take care of her, a promise he said he intends to keep.

10. Saman and his father Amarasiri

Saman provides care for his father, who had had dementia for five years prior to the interview. Amarasiri is now bed ridden and has lost his ability to communicate or to address his personal needs. Saman reported that he visits his father daily and spends his entire afternoon with him. All his personal care including feeding, bathing, dressing, toileting and cleaning up is undertaken by Saman when he visits. It appeared that in his absence his mother, Piyaseeli, does the feeding or cleaning up if necessary, but she is unable to turn her husband or change his position due to old age and physical weaknesses. Saman reported that he is overwhelmed by work and caregiving responsibilities, but continue to provide care as he loves his father very much.

11. Nimala and her husband Dayasiri

Nimala is a retired professional, currently involved in full-time caregiving for her husband, who has dementia. They live in a shared house with their daughter. Their son lives next door and constantly attends to his parents' needs. The family first noticed Dayasiri's personality and behavioural changes about four years prior to the interview. They had initially ignored such signs but had later registered at the

dementia clinic. Nimala said she prefers taking treatments from their family doctor (private channelling), so she stopped attending the dementia clinic at the hospital.

Nimala reported that some days Dayasiri behaves like a child - touching the mud, playing with water, and collecting stones and shiny items. She said her efforts to prevent him doing this often precipitates disturbing reactions, including screaming and getting agitated. She seemed very concerned about continuing to care for him in the future, rather than placing this burden on their children, as Dayasiri has gradually begun to neglect his personal care and is losing the ability to cooperate with her.

12. Niluka and her father Siril

Niluka is the main caregiver for her father, Siril, who has dementia. She is the only child in her family, married with two daughters. She said her father was a chronic alcoholic for many years; therefore, the doctors suspect his heavy drinking may have caused neuronal damage resulting in dementia. She reported that since her mother died she is solely responsibility for her father's care and none of the family members support her.

Two weeks after I interviewed Niluka, she called to say that Siril once ran away from home but no one supported her to find him, including the family and the police. After this incident she finally managed to appraise the doctors at the dementia clinic of her current situation and the family disputes regarding Siril's care. They subsequently helped her to admit Siril to the mental hospital to receive advanced care and he died in the hospital few days later. Niluka is currently being treated for mild depression.

13. Dinesh and his mother Leela

Dinesh and his two brothers have never had a good relationship with their mother Leela due to long term family conflicts. He has never approved of his mother's behaviour as he thought it disgraced the entire family. By the time of interview Leela lived by herself and Dinesh was only providing her with meals and money.

One of her sons took Leela to the mental hospital and also got her registered at the clinic, but she has not been referred for further investigations and was not receiving any treatment for her forgetfulness at the time of interview.

When first contacted, Dinesh did not wish to take part in the study but he later visited IRD for the interview unexpectedly. It was during this interview that Dinesh first heard about dementia and began to realise that his mother's behaviours were the result of an illness. At the end he cried because he had treated her badly over recent events and said he is going to forgive her and start treatments as soon as possible.

14. Rose and her husband Basil

Rose had been married to Basil for 20 years; they were both retired professionals and have one daughter. According to Basil he *'dedicated his life to his work'* and retired nearly two years prior to the interview. Since his retirement he has developed mild depression and was treated with medication. According to Rose he suddenly got ready one morning as if he was going to work and said that he needed to carry out some work at a workplace where he was based many years ago. This incident first alerted the family to his forgetfulness. Rose said he was hospitalised and later diagnosed with dementia.

Rose reported that he cannot remember recent events and at times also forgets personal information, such as names of items or family members or shows lack of interest in his usual hobbies, such as reading and singing. She also said that until very recently he managed to visit the market or nearby places but now shows decreased ability to travel alone. However, Basil appeared to deny his forgetfulness and becomes irritable and agitated when family members try to remind him of things. Rose appeared very concerned about leaving him alone at home while she is at work and their daughter said she is not ready to face her exams and she cannot leave her father at home.

15. Premasiri and his elder brother Siridasa

Premasiri and his wife provided care for his brother, Siridasa, for nearly four years. Siridasa died due to very severe dementia at age 75, about a year prior to the interview. When I first contacted them, Premasiri and his family said they still wanted to take part in the study and share their experience as it was the first time *'someone shows an interest to ask'* how they felt about it. When reflecting back on the experiences, Premasiri said he had a huge responsibility regarding the care and safety of his brother as he often ran away from home.

Indu (Premasiri's wife) reported that another reason for them to take part in the study was to share their experience and update their knowledge regarding the illness as they suspect that their mother is now in an early stage of dementia as she has recently started exhibiting similar behaviour.

16. Jayanthi and her sister Gunawathi

Jayanthi, is a retired health care professional who volunteered to take care of her elder sister, Gunawathi. Gunawathi was an 85-year-old widow, had no children, and lived alone for nearly 13 years after her husband died from dementia. She earned a living by weaving mats and tapping rubber in her own estate. About eight years prior to the interview she had a fall and fractured her leg, following which she moved in with Jayanthi and her family.

Jayanthi reported recently noticing certain behavioural changes and suspects it could be early signs and symptoms of dementia. She explained that Gunawathi often forgets whether she had her breakfast or combed her hair. She sometimes shouts at Jayanthi for trivial matters, saying she is the worst sister anyone could ever have. With her experience being a health care professional and her previous experience with Gunawathi's husband who also had dementia, Jayanthi understands the importance of seeking medical advice as early as possible. However, Jayanthi said she is not interested in registering at the dementia clinic but instead plans to take her sister to see the family doctor soon. I was introduced to this family by another study participant.

17. Gayan and his mother Saralin

Fifty-year-old Gayan, and his wife Lakmini, provided care for his mother, Saralin who had dementia. According to Gayan, Saralin was a very independent and authoritative woman. However, she started hiding items such as toothpaste or food. Then she started stealing things from her neighbours, plucking flowers or fruits from neighbourhood gardens and denied this when they asked about it. Saralin was an active member of a social welfare club, based at the temple, before

she started experiencing symptoms, but was later she was cut-off from the club and not invited to any events.

On the recommendation of a relative Lakmini has taken Saralin to the mental hospital. She was diagnosed with dementia and registered at the dementia clinic about six months prior to the interview. Currently Saralin does not attend the clinic. Instead a family member visits the clinic on a monthly basis to collect her medication. Up to now Saralin has lived separately as she was not on good terms with Gayan, due to a conflict they had some time back. However, Gayan and his family live next door, providing care for her despite all the past incidents.

18. Mallika, Kanthi, Neela and their mother Sheela

Mallika is 71 years old, a retired health care professional, and the eldest of ten children. Mallika's two sisters Kanthi and Neela reported that the female siblings together look after their mother, Sheela, who has dementia. It appeared that the brothers are not involved in Sheela's care. Because of her professional background Mallika has taken on a greater proportion of the care responsibilities. However, due to her age and current ill health the other sisters attend to most of Sheela's physical care needs. Mallika is in-charge of decision making on Sheela's treatments. They also have support from a paid caregiver during the night time as none of the daughters live in the same household as their mother.

The sisters reported that their mother always asks about the brothers but they hardly visit her. There had been arguments and family disputes over this matter. Kanthi and Neela find it difficult being full-time caregivers as they have other responsibilities in their own households.

19. Soma and her former housemaid Nimalawathi

Soma is a retired professional who is caring for her former housemaid Nimalawathi, who has dementia. Nimalawathi was just 20 years old when she first met Soma, and since then she has served the family over 40 years. Soma explained that Nimalawathi has looked after the entire household, and raised Soma's three children and grandchildren, until she developed confusion and forgetfulness (which Soma referred to '*madness*').

Soma said that Nimalawathi has recently become overly dependent on her and very disoriented in the home environment. She cannot recognise the family members anymore, she often forgets things such as eating and dressing and shows difficulty in finding her way to her room, the toilet or to the kitchen. Recently she has also developed incontinence.

Soma and her children have decided to take care of her for the rest of her life as reciprocation for her long-term service to their entire family. Soma's children support her financially and with transport facilities, but they all live away from home. Soma finds it challenging to attend to the increasing care needs as she too suffers from several illnesses, including arthritis and hypertension.

20. Samanmali and her mother Rosalin

Samanmali is a 55-year-old unmarried entrepreneur, the only child in her family. Since her father died Samanmali and her mother have lived together in their house. Samanmali said she went on a pilgrimage, leaving her mother to a relative for about three weeks. When she returned she noticed her mother's strange behaviours. Rosalin demonstrated a lack of orientation to time, and started cooking meals in

the early hours of the morning. Most of her conversations were about what she was doing in her thirties, and she was behaving as if she was living in her past. She often had arguments with Samanmali, complaining she cannot find things and blaming her for this.

Samanmali seems to be an extremely religious person. She does not seem to favour western medical care, and has therefore disregarded others' assumptions about her mother's illness and refused to seek medical advice, as it contradicts her religious beliefs. Instead she has used numerous traditional remedies, influenced by her culture and religion, as instructed by a monk.

5.4 Chapter summary

This chapter has provided an overview of each family that participated in the study. This included socio-demographic information of the participants and the current situation of the care environment. In line with IPA approach, developing these narrative descriptions enabled me to capture the whole experience of each individual caregiver before I look at the entirety of the interviews. The narratives also provide context for interpreting caregivers' perceptions, views and experiences that will be reported in the subsequent chapters.

Chapter Six
Meaning of dementia

Chapter Five presented socio demographic information relating to each of the study participants and narrative descriptions of the context surrounding each individual family. This chapter presents findings on the first superordinate theme identified from the analysis: 'meaning of dementia'. This superordinate theme comprises of two themes, which will be discussed in turn: 'Illness perceptions' and 'Perceived causes of dementia'.

6.1 Illness perceptions

Illness perceptions are the 'organised cognitive representations or beliefs' that the people have about their illness (Petrie, Jago and Devcich, 2007, p.163). The theme 'illness perceptions' in this thesis describes how the informal caregivers identify, understand, define and interpret the nature of dementia including forgetfulness and behaviour and psychological symptoms of dementia (BPSD). The participants appeared to have different views and perceptions towards dementia. The theme 'illness perceptions' is described through three subthemes: (a) "It is not an illness but a normal part of ageing"; (b) Illness identification; and (c) Denial.

6.1.1 "It is not an illness but a normal part of ageing"

Reflecting back on the time prior to diagnosis of dementia and their earlier views and experiences, with the exception of three main caregivers, all others reported that they missed most of the early signs and symptoms of dementia at the onset due to their lack of awareness of the condition. The study participants explained, they *'didn't recognise'* the behavioural and psychological changes as early signs and

symptoms of dementia because they '*didn't know*' or '*hadn't heard*' about dementia at the time the person with dementia (PwD) began to display forgetfulness or early BPSD:

"*Those days she was always like, 'my purse is missing! Bank card is missing...! I've lost my necklace!' But I didn't take much notice of it..." (Kumari, 47y: Daughter-in-law, Main caregiver [MC])*

"None of us had seen or heard of such a thing before. No one in our family had this kind of illness. I don't think any of us had a clear understanding of the illness even though we were asked [by relatives and friends] to take him to the mental hospital." (Rani, 52y: Daughter, MC)

Lack of awareness by the caregivers is one of the reasons for missing the opportunity of noticing BPSD and choosing not to seek treatments at early stages. Not only at the onset, but still at the time of interview, some caregivers appeared to believe that the forgetfulness and BPSD they observed were a normal consequence of ageing, and therefore they considered treatments for BPSD to be unnecessary. There was variation amongst participants. For some, once the diagnosis had been explained to them, they accepted these signs and symptoms as dementia, but for others their earlier views still persisted despite their increased awareness of dementia. For example, a secondary caregiver reported that she attributed her sister's symptoms to 'normal' forgetfulness experienced in old age:

"I think this [forgetfulness] is normal… Even I forget certain things sometimes… Even you my child, may go through the same when you get old." (Dayani, 76y: Sister, Secondary caregiver [SC])

Another common perception among the caregivers was that elderly people develop *'child-like behaviours'* and *'engage in childish activities in order to seek attention'* when they grow older:

"She has a child's mentality now. I think that's why she likes to be with children."

(Samanmali, 55y: Daughter, MC)

"She is very much attention seeking now. She screams with no reason, talks loudly. I think it's all because of her age… Most of her behaviours are so childish."

(Chandrika, 60y: Daughter, MC)

6.1.2 Illness Identification

The second subtheme which emerged under the theme of illness perceptions was 'illness identification', which describes how the caregivers identified and labelled dementia at the time of the interview. Illness identifications ranged from *'madness'* to *'some kind of mental illness':*

"It is madness. She walks around the house and wakes up the kids at night. Sometimes screams, cries on unnecessary matters. Complete madness!" (Soma, 71y: Former Employer, MC)

Caregivers appeared to relate dementia to their existing knowledge, experiences, values and attitudes when labelling the condition. Some family members recalled films or television dramas which featured characters that had similar characteristics, but beyond this most of them had no clear understanding of the nature of dementia:

"Now I know all his current behaviours are because of this illness... But early days I didn't know. […] I remember my son showed us a film about a person who has similar behaviour. […] The doctor didn't tell us the word 'dementia'… he only said it was a mental illness." (Rani, 52y: Daughter, MC)

The main resource for caregivers to learn about dementia came from the doctors they consulted. However, it appeared that there was no definite label given by the doctors to assist caregivers in understanding the condition at early stages. The level of knowledge varied from person to person, even among the individuals in the same family. For example, those who attended the dementia clinic regularly understood the nature of dementia better than the others and could also explain the pathological causes of dementia during the interviews:

"It was at the mental hospital I got to know it's due to neurone damage. The doctors told me the reason for this. Her brain cells are damaged and now this can't be cured..." (Soma, 71y: Former Employer, MC)

"Doctors told us memory loss is due to nerve cell damage and death of brain cells... They told us the lost memory can't be retrieved." (Edwin, 68y: Brother-in-law, SC)

In all of the interviews the participants were asked whether they could name the medical condition that the person they cared for was diagnosed with. Only seven main caregivers could state or remember the term 'dementia' and the majority of the secondary caregivers appeared to be still unaware of the condition. In some cases, the caregiver who attended the clinic was aware of the dementia diagnosis but had not communicated this to the rest of the family including the main

caregiver due to lack of clarity of the information received from the clinic (e.g. Sena's Story, See page 269, in Chapter Eight, Section 8.2).

Although caregivers' experiences of living with the PwD caused then to react in different way to the BPSD from time to time, the nature of dementia was still not understood by most of the secondary caregivers. However, caregivers showed an increased level of understanding of the early signs and symptoms of dementia at the time of interview if they had previously cared for a person with a mental illness or dementia as a health care worker. Three of the main caregivers who were also health professionals said they identified the "condition" as dementia at the very early stages (even before medical diagnosis) and were able to identify the signs and symptoms of dementia when they initially noticed them. A higher level of awareness appeared to motivate these caregivers to seek medical advice at the early stages of dementia and to attend the dementia clinic and select the medical model (western medicine) as the first line treatment method. Jayanthi, a retired nurse who provided care for her elder sister, said:

"As a nurse I know this is an illness. As I think she is in the very early stage of dementia… With her age, it's better if we take medicine at the beginning… It's good for the patient. I think it [treatments] will also reduce the trouble we will have with her in the future." (Jayanthi, 66y: Sister, MC)

The majority of main caregivers could relate to the condition as an illness (or more precisely a mental illness) by the time the interviews were conducted. However, out of the twenty main caregivers interviewed, fifteen accepted that they did not know the condition as 'dementia' until they attended the dementia clinic or heard the term during the interview:

"Now I know this is dementia because every month I attend the dementia clinic for him... I can teach someone else now, ha haa! [laugh] But those days I knew nothing about dementia..." (Saman, 48y: Son, MC)

The caregivers highlighted the challenges caused by failure of illness identification, the barriers to raising awareness, and their need or wish to receive more information about dementia. Chapter Eight will present the findings related to issues and challenges caused by caregivers' lack of awareness.

6.1.3 Denial

In addition to the lack of understanding and unawareness it appeared that some caregivers currently refuse to accept forgetfulness and BPSD as clinical features of a mental illness requiring medical treatments. A daughter said that her family *'did not want to accept'* her father's dementia as they *'did not notice any difference'* in his behaviour or *'did not know'* what he had been doing when he was away. It appeared that the family were reluctant to accept the diagnosis, because of the fact that they were unaware of the full extent of his forgetfulness when this first began:

"Although someone suggested that father had a mental illness, I think none of us wanted to accept that… We didn't pay too much attention to it. […] We didn't notice any difference in his thinking capacity. Those days we let him go out whenever he demanded to do so... And he somehow returned home from wherever he went... We didn't realise that he forgets the way home." (Niluka, 38y: Daughter, MC)

Some caregivers denied dementia, and also failed to notice some of the behavioural and personality changes as early signs of dementia. Denial was a commonly reported perception among most of the caregivers at the early stages of caregiving,

but later they appeared to change their perspectives and accept that dementia needs treatments:

"We didn't think he was ill. He caused much trouble in our families. He turned in to a tell-tale and made snide comments to his sons-in-laws. We all thought he had turned into an unpleasant person. We didn't know about an illness." (Rani, 52y: Daughter, MC)

Whilst the extracts above relate to caregivers reflecting on their views towards dementia when their family member first began to exhibit signs of the condition, it was evident that many of the main caregivers and family members refused to accept or acknowledge dementia by the time of interview, even though they had been providing care for a PwD for a considerable period of time. Some appeared to have lack of insight or continue to deny the condition in spite of their experience and long-term involvement in caregiving. A main caregiver who refused to acknowledge his wife's dementia remained in denial, despite gaining at least some awareness of the illness:

"I blame [his daughter] for taking her [the PwD] to hospital. In vain she swallows many pills for nothing. There's no such thing [dementia]. There's nothing wrong with this woman. [Angrily] She is FINE." (A Husband: MC)

Some caregivers appeared to believe that the affected person was deliberately behaving inappropriately and pretending to have dementia in order to bring shame on the family members. This belief was common among the caregivers who denied the presence of BPSD and refused to accept dementia as an illness. However, such beliefs and assumptions were most likely to be expressed in situations where

caregivers and the PwD did not have a good relationship prior to the development of dementia. Some of the family members (including three main caregivers) appeared to think that the PwD was *'acting, lying, cheating, being attention seeking or pretending to be forgetful in order to escape from their routines or responsibilities in the household*'.

Personality changes were often misinterpreted by the caregivers as *'bad manners'* or *'deliberate activities'*. Reasons for misinterpreting dementia as *'acting as if forgetful'* were the attitudes of family members towards such behaviours, previous similar incidents (e.g. telling lies) and also the inconsistent nature of dementia:

"She lied to me many times. She says she can't see anything, but she sees my grey hair… [Laugh sarcastically]. But she can't remember her meal times, even her tea time." (Samanmali, 55y: Daughter, MC)

It appeared that previous incidents such as arguments or family conflicts, and what the PwD had said and done such situations before developing dementia, had a significant influence on the assumptions caregivers made regarding the BPSD. Memories of such incidents and comments made during the arguments often caused misunderstandings and negative attitudes towards the current BPSD of the PwD. The interviews with caregivers revealed that the family members attempted to compare such pre-dementia incidences with the present behaviour of the PwD. The current behaviours were interpreted as intentionally, hurtful, vengeful or designed to bring shame to the caregivers by causing social disgrace. For example, a son said his mother is a *'drama queen'*, strongly believed his mother is trying to '*bring shame*' on his family or to '*humiliate them in public*' as she had once sworn to

'*take off his clothes in public*' during an argument in the past, before her dementia diagnosis:

"Drama queen…! She is a drama queen. All her life she acted very well. And this time she is acting to be insane to get the attention from the neighbours so she can tell others what a bad son I am who doesn't care for her. […] She is a drama queen… She lies...! She even remembers about the money I owe her from a long time back. Now she pretends that she can't find her way home. [Angrily] Drama queen…!" (A Son: MC)

However, it appeared that his assumptions and behavioural attributions arose due to his lack of dementia awareness, his inability to understand the inconsistent nature of dementia and her previous premorbid personality; that is, how his mother could remember things from a long time ago, yet forget everyday things happening in the present. His present attitudes caused misunderstandings, anger and frustration and often led to give up caring for her. This particular caregiver also reported that he had not heard about dementia before:

"DEMENTIA WHAT? This is the first time I heard about it... Dementia... Huh! [Sounds doubtful] I thought she is pretending… Do you think it's really because of an illness? [Laughs angrily, …] I hardly believe this woman has an illness. I am sick of her drama." (A Son: MC)

It also appeared that in some families there is a clear difference between the views of the main caregivers compared to rest of the family members who have a less central role in caregiving (secondary caregivers). The family members who were

not directly involved in care were more likely to think that the behaviour of their loved one was '*intentional*' as they were less informed about dementia:

"They [husband and some relatives] say he is lying and pretends to be forgetful. […] Sometimes he has a very good memory. You know, on and off... He remembers things that we cannot even recall [past incidents]. When he does such things they think he cheats, because they have no idea about the illness." (Rani, 52y: Daughter, MC)

According to above quotation, Rani appeared to have a good knowledge and understanding of dementia, but her husband who was mostly away from home thought that her father was acting:

"I think he is lying, cheating and deliberately behaving so… Good acting, hah!" (Rani, 52y: Son-in-Law, SC)

It appeared that inconsistency of BPSD confused the caregivers. Some reported that it was a '*dilemma*' deciding whether these were deliberate acts or actual symptoms of dementia:

"Um... I can't exactly say whether it's forgetfulness or not… She can walk inside the house and find her room without help. But she doesn't use her toilet right next to her room. Instead she does it [pass urine] here... in the living room..." (Chandrika, 60y: Daughter, MC)

"Sometimes I wonder whether he troubles us deliberately as he is angry with us... We don't know what he thinks. I'm confused as he has once told my husband that he won't let us live peacefully…" (Niluka, 38y: Daughter, MC)

6.2 Perceived causes of dementia

The second theme 'perceived causes of dementia' presents the views of the caregivers in relation to possible causes for their family member developing symptoms of dementia. This theme contains two subthemes: (a) stressors (or life circumstances) and (b) cultural and religious factors reflected through beliefs. In most situations the participants drew on more than one cause in their explanations.

6.2.1 Stressors

The subtheme 'stressors' describes the co-occurring factors such as lifestyle, having a chronic physical or psychological illness, and stressful life events for the PwD, which the caregivers thought of as the causes of forgetfulness or behavioural and psychological changes presented by their loved one in later life.

Whilst the majority of caregivers had not heard of dementia prior to the interview, they appeared to be informed regarding other conditions and spoke about the causes, and attributed the symptoms, to those co-morbid conditions instead of accepting BPSD as part of dementia. They reported that the symptoms (for example, forgetfulness) were caused by pre-existing physical conditions or chronic illnesses (such as hypertension, diabetes, arthritis, epilepsy, head injury) and also psychological conditions such as anxiety or depression. Due to lacking understanding of dementia the caregivers appeared to believe their loved one's BPSD were caused by one or more of these conditions. Some caregivers said, the development of forgetfulness may be an outcome of prolonged medication for the aforementioned health conditions:

"From the day I can recall, this woman swallowed pills for that and this [other physical conditions]. If you collected them, you could've loaded a container… I say, that's why she developed this. Is it good to have this much of chemicals? I blame her… Her fault." (Jinadasa, 72y: Husband, MC)

"I think his [depression] is responsible for this forgetfulness." (Sarah, 18y: Daughter, SC)

"She used to get fits [had epilepsy since childhood] ... There was a time when she didn't have a single attack... for about a year and a half. Only then she developed this [memory loss]." (Sena, 72y: Husband, SC)

Some of the caregivers blamed the PwD for not taking care of them-selves and not taking actions to minimise the risk factors for developing dementia in later life:

"He was careless. He knew he was a heart patient, but never took his pills on time. He was so stubborn and never listened to us either… In a way he is responsible for his current situation." (Saman, 48y: Son, MC)

Some main caregivers believed that previous trauma or head injury caused memory loss:

"I have no idea why and how she got it… Perhaps because she fell down several times. I remember she injured her forehead once... She even passed out that day…" (Chandrika, 60y: Daughter, MC)

A daughter reported that her mother's forgetfulness and *'weird behaviour'* developed as a result of long-term physical abuse by her father:

"My father used to hit her. Sometimes he might have hit her head too... It might be the reason." (A Daughter: MC)

Some reported that the PwD's previously unhealthy lifestyle caused dementia in later life. They said that the doctors they consulted confirmed some of their assumptions. The reported characteristics of unhealthy lifestyles include: lack of work-life balance, work without a rest when they were fit and well, and habits such as prolong smoking or drinking.

"Our mother was working so hard to raise us ever since our father died. May be that hard life caused her this illness." (Neela, 62y: Daughter, SC)

"Sometimes I think whether his heavy drinking caused this. I'm not sure... but his mind is now destroyed. The doctor said most of the neurones in his brain are dead now as a result of drinking..." (Niluka, 38y: Daughter, MC)

Emotional crises such as loneliness, prolonged suffering, over-thinking, and certain life events that affected a person psychologically (for example, sudden death of a close family member) were also reported as possible causes of forgetfulness and personality changes in old age. However, in such cases the caregivers were not linking the forgetfulness to dementia, but attributed the symptoms to the psychological crises experienced by the individual:

"I think... She is lonely as she hasn't got anyone to talk with. It is her loneliness that brings all the sickness and complaints." (Samanmali, 55y: Daughter, MC)

"Mother was in shock after our sister died… She changed a lot since then... Yes... It got worse after Father died. I wonder whether that affected her brain badly." (Lakmini, 48y: Daughter-in-law, SC)

It appeared that some caregivers blamed themselves for the circumstances perceived as leading to the family member developing dementia:

"When we all got married and left home, she was lonely. On top of that she was worrying about my brother's ill health… I think those were the reasons for this [forgetfulness]…" (Neela, 62y: Daughter, SC)

"She is overly worried about certain things. Her husband sometimes yells at her, so she is unhappy... Perhaps… such things might have affected her mind badly." (Dayani, 76y: Sister, SC)

6.2.2 Cultural and religious factors reflected through beliefs

The second subtheme that describes the theme 'perceived causes of dementia' is 'cultural and religious factors reflected through beliefs'. It appeared that the faith, myths, and cultural and religious beliefs held by the caregivers play a significant role in determining their perceptions of illness causation, interpretation and attribution of symptoms. This subtheme explored the cultural and religious concepts which were considered as the causes of dementia. They are namely; *Karma* or God's wish, fault of the stars, and revenge.

(a) "Karma" or "God's wish"

The overwhelming majority of the family caregivers who took part in the study were Buddhists. They appeared to believe that their loved one developed dementia as a result of *'Karma', 'law of Karma', 'sins'* and *'merits'.* According to Lord Buddha's teaching *Karma* means 'action, performed with intention' (Obeysekere, 2002; Sethabouppha and Kane, 2005). Caregivers' interpretation was that *Karma* can result from physical, verbal or mental action, and that good actions will lead to

good consequences while bad actions lead to bad consequences in this life or in future lives. They referred to the good actions or acts of merit as '*pin*' and the bad actions or acts of sin as '*paw*'. Buddhist caregivers also seemed to believe in reincarnation. According to their views the acts of merit and sin determine one's *Karma* and the outcomes of *Karma* can be experienced in this life itself or in a future life. What is experienced in this current life is a result of the *Karma* brought from previous lives (Sethabouppha and Kane, 2005). This cycle is called *'*the law of *Karma'*. The notion of the unsatisfactoriness of existence, suffering or '*dukkha*' is primarily generated through *Karma* (Obeysekere, 2002). One's health, illness, wealth and quality of life are all results of the *Karma* brought forward from previous lives:

"This has to be some kind of sin she committed in her previous life. She was someone who helped each and everyone in this life." (Soma, 71y: Former Employer, MC)

"Mother observes at Sil [a religious ritual] from a long time. [Some people] ask us how this happened to her even after living such a good life..." (Chandrika, 60y: Daughter, MC)

The two examples above also show the caregivers' efforts to portray their loved ones positively through emphasising that they have lived well in the present life; rather their Karma is based on sins in a previous life, which is out of their control. This also emphasise that the negative *Karma* needs to be paid off in their present life, regardless of the merits they have collected in their present life. It also gives the impression of inevitability, rather than something that can be changed or modified:

"It's Mother's Karma... She used to be so religious in this life but now, some kind of bad Karma is in front of her. We can't avoid this, can we? She has to take it." (Neela, 62y: Daughter, SC)

"This is what she brought from her previous life. No one can escape from Karma." (Sena, 72y: Husband, SC)

Among the participants there were only two caregivers from a Catholic background. While the Buddhist caregivers appeared to believe that *Karma*, merits and sins cause dementia, Catholic caregivers said they believe that '*it's the God's wish*' according to their religious beliefs:

"As my husband says, It's the God's wish!" (Rani, 52y: Daughter, MC)

"God only knows why this happened to her... Perhaps it's all his plan." (Nelum, 66y: Sister, MC)

As with the Buddhist concepts of *Karma,* impermanence, and as with the Catholic concepts, the inevitability that it is *'God's wish'* appeared to provide some comfort and a cultural way of coping to the caregivers and allowed them to come to terms with the deteriorating nature of dementia.

(b) "Fault of the stars"

Some of the caregivers appeared to believe that dementia was caused by bad planetary alignments (i.e. the twelve signs of the zodiac, the sun and moon) or the astrological influence on the PwD and their family members. It is a common cultural belief among people in Sri Lanka that difficult times and illnesses are caused by the bad positioning of stars (or planetary bodies) according to an

individual's birth time. Caregivers described this concept using the terms such as '*bad stars, fate, destiny and bad luck*' of the PwD:

"Her stars are so badly aligned... Astrologers said, this is a very critical time for her, her stars will cause her illnesses and give mental problems during this time." (Sena, 72y: Husband, SC)

"It's his destiny. His star alignments are so bad..." (Piyaseeli, 68y: Wife, SC)

Three families appeared to believe that the astrological misalignment issues in the house called '*Vasthu dosha*' (which means the architectural issues related to astrological misalignment of the building) caused dementia. For example, a main caregiver appeared to have strong beliefs that the problems including his mother's dementia were a result of living in a house full of '*Vasthu dosha*':

"As I see it... This house is full of 'Vasthu dosha', that's why my mother is ill. This house has been built without an auspicious time… against the astrological guidance." (Kelum, 31y: Son, SC)

The caregivers appeared to believe that the astrologers can predict the course of illness as well as possible hard times for individuals in advance, based on the planetary positioning or birth time and zodiac sign of those individuals:

"A monk told me this house is not good for living... Not only mother's, it will ruin all our lives. So, I immediately changed the plan and rebuilt it according to his guidance." (Gayan, 50y: Son, MC)

In contrast to the explanation of *Karma* or God's wish, the caregivers appeared to believe that something can be done to correct the influence of stars and cure the

condition. Despite the understanding of inevitability, they also appeared to cope and comfort themselves by self-validation of "doing" something rather than just waiting and observing (in this case practicing astrological remedies). Reported astrological remedies for dementia were mainly of three types: horoscope readings and do the needful as advised by the horoscope reader to modify the influence of stars (e.g. wearing a ring with a specific gem or an amulet), offerings to deities and correcting of astrological misalignments of the house. Chapter Seven, Section 7.2.2, will further describe the relationship of religious and cultural beliefs and related care models when defining the meaning of caregiving (See pages 214-222).

(c) "Revenge"

Another perceived cause of developing dementia was as a result of 'revenge'. Three common beliefs were reported by the caregivers:

- The PwD developed dementia intending to take revenge on the family members.
- Dementia is caused as a result of possession by evil spirits or dead relatives who try to take revenge through the PwD on the family members.
- Dementia arises as a result of witchcraft (black magic, evil eye, evil tongue) or curses made by enemies or rivals of the family or the PwD.

Some of the study participants reported that, in a previous life, the particular PwD might have been determined to take revenge on the caregivers following their next birth, so now they have developed dementia so that the family members suffer by living with, and having to care for the PwD. For example, Gayan appeared to believe that his mother was intending to take revenge on him in a previous life, and that

she still has this intent and is still to blame despite the revenge relating to a previous life.

"This is a revenge that comes from bhawa [series of previous lives]. Mother wants to take revenge on me and she became like this." (Gayan, 50y: Son, MC)

The cultural beliefs and myths, such as the influence of supernatural spirits, dead relatives, gods or deities, predominantly influenced the caregivers' views on the perceived causes (Schoonover *et al.*, 2014). The majority of the caregivers who held such beliefs reported that dementia might be caused by a supernatural evil spirit who intended to take revenge on the family through the PwD. According to them, the spirits of dead relatives have returned as they want to take revenge on the person and the family members, or alternatively they have possessed the affected person as they were so attached to them:

"My late sister was so attached to her [the PwD], but we didn't see eye to eye. I think she tries to take revenge on me through my mother... This is a possession." (Gayan, 50y: Son, MC)

"Dead spirits of my late father, aunt and grandmother... They [spirits] caused much trouble. Mother's mind was possessed by their evil spirits. There were many issues here by the time I returned from [pilgrimage]... I mean she wasn't eating anything... she tried going out during night… she was behaving strange." (Samanmali, 55y: Daughter, MC)

The caregivers reported that certain habits such as regular consumption of tempered meat or fish, not following the religious rituals at home and the untidiness of the household attracts evil spirits, and if the supernatural spirits are

angry with people then they will take revenge by causing illnesses. Some caregivers tended to blame the PwD for attracting evil spirits because of their untidiness; which also had negative consequences for caregiving:

"She doesn't wash the cooking pans well and her kitchen is bad smelling... Doesn't sweep the house regularly... So, it's very likely that the bad spirits are attracted to her when the home isn't clean and tidy. […] It's not a good thing to offer foul food to Lord Buddha [offering meals to Lord Buddha is a Buddhist ritual]. Some days I have seen she offers rotten meal to Lord Buddha…" (Lakmini, 48y: Daughter-in-law, SC)

Some caregivers related to the onset of BPSD as a near death experience. They believed that when people are close to death the dead relatives visit them and invite the living person to join them. Signs and symptoms such as hallucinations and delusions were often misunderstood as the affected older adults talking with evil spirits and dead relatives who visit them. In such situations the remedies were to follow traditional healing methods to chase away the dead spirits:

"We thought she was troubled by dead spirits. She is being cursed... Possessed by her dead mother. She even talks to them so often... we can't see them, only she can."

(Sena, 68y: Husband, SC)

Traditional beliefs on witchcraft such as black magic, evil eye and evil tongue were predominant cultural beliefs that associate the concept of revenge and causation of dementia. The caregivers appeared to believe that the PwD and the family were being cursed by someone, or they were subject to witchcraft such as the evil eye, black magic or being put under a spell by someone (usually a rival relative or neighbour who seeks revenge on the family), hence supernatural powers caused

illness for the PwD, leading to a hard time for the entire family. They also appeared to believe that casting a spell or curse can harm, cause illnesses such as dementia or even cause death of the affected person or the entire family:

"[Witch doctors] said [an enemy] has done a 'Bahirawa Bandana' [a witchcraft] to kill all of us... Their plan was to chase us away from this house so they can own it... That killed my father-in-law... my husband died a month later... and now my mother-in-law got this illness... Perhaps it will kill us too..." (Kumari, 47y: Daughter-in-Law, MC)

The influence of caregivers' religious and cultural background on their caregiving will be presented in Chapter Seven, Sections 7.2 and 7.4.2.

6.3 Chapter summary

This chapter presented findings on the first super-ordinate theme identified from the data: 'meaning of dementia'. Two themes emerged from the data: the illness perceptions and perceived causes of dementia. The illness perceptions held among the family caregivers, ranged from not recognising signs and symptoms as relating to an illness, perceiving forgetfulness as a 'normal' part of ageing, denial of BPSD (e.g. deliberate actions of PwD). Most of the caregivers identified and labelled the signs and symptoms as 'madness', 'a mental illness', or 'an illness caused by neuronal death or injury' while a few recognised this as dementia. The second theme 'perceived causes of dementia' consisted of two subthemes: stressors, and cultural and religious beliefs. The subtheme 'stressors' presented the caregivers' perceptions related to co-occurring factors such as lifestyle, chronic physical or psychological illnesses, and stressful and traumatic life events such as loneliness

or death of a family member. Caregivers drew on a range of religious or culturally accepted concepts to explain the cause of dementia; such as, *Karma', 'Pin', 'paw'*, 'God's wish', 'bad stars', 'astrological misalignment of the living house', 'possession of supernatural spirits', or 'witch craft'. Caregivers' low levels of knowledge and awareness as well as their beliefs, thoughts, assumptions and attitudes influenced by culture and religion appeared to have an association with the attributed meanings.

'Blame' was associated with illness perceptions and perceived causes of dementia. Caregivers tended to place the blame on the PwD for their behaviour if they were unaware of BPSD or denied the symptoms of dementia. Some tended to blame themselves, other family members or the perceived causes they thought of as the causes of dementia (e.g. Karma, fate, supernatural spirits, witch crafts). Caregivers' illness perceptions and causation explanations appeared to shift over time with a longer period of caregiving as a result of continued exposure and increased awareness. The next chapter will present findings on the meaning, practice and purpose of caregiving for a PwD.

Chapter Seven

Meaning, practice and purpose of caregiving

This chapter presents the second super-ordinate theme 'the meaning, practice and purpose of caregiving'. Four themes emerged from the interpretative phenomenological analysis (IPA) in order to capture the essence of the super-ordinate theme, namely: (1) connectedness, (2) engagement, (3) control, and (4) 'awakening'. The findings reveal the views and experiences of main caregivers and other family members in relation to their role, level of involvement and engagement in caregiving activities, the meaning assigned to the activities performed by them, and also the perceived impact upon quality of caregiving and quality of life for the person with dementia (PwD) and the caregivers.

Caregivers' thoughts, beliefs and attitudes towards the meaning, practice and purpose of caregiving seemed to be directly influenced by their illness perceptions and their understanding of the causation of dementia. This chapter therefore builds on the views and perceptions discussed in Chapter Six.

7.1 Connectedness

The theme of 'connectedness' refers to the various types of connections or relationships developed, both within the family and the wider social circle through caregiving. This theme encompasses both the positive and negative impacts of connectedness between the PwD, main caregivers and others who are directly or indirectly involved in the caregiving process under two subthemes: (a) togetherness and (b) communication.

7.1.1 Togetherness

This subtheme presents evidence of togetherness and also lack of togetherness or 'distance'. For the majority of informal caregivers 'togetherness' was one aspect of the meaningfulness of caregiving. There is evidence for strengthening of relationships within family, a particular group, or community in terms of sense of belonging, affinity and union as a positive impact of dementia. The concept of togetherness was described by the study participants by phrases such *as 'connecting with each other', 'a bonding moment', 'team up', and 'becoming close'.* The caregivers considered positive consequences of togetherness as *'a blessing in disguise', 'happiness'* or *'a wonderful experience':*

"I feel happy to spend the day with my father… It's mostly my father and I are at home during the day time. So, I get to spend more time with him… you know, more father-daughter time." (Rani, 52y: Daughter, MC)

"We, the five sisters teamed up to take care of her. I think in a way her illness became a blessing in disguise. I mean, it brought us [the family] closer... She was alone in this house and now she is our main focus." (Neela, 62y: Daughter, SC)

"Both the children got married and separated from the family. My husband and I were lonely, Umm… It occurs to me... somehow, this situation brought us back together, much closer than we were used to be. It's wonderful." (Piyaseeli, 68y: Wife, SC)

Togetherness appeared to reflect *'spend[ing] time together'*, *'to support'*, or *'to share memories'* in the sense of social interactions. Some families who took part in the study perceived the act of caregiving as a team effort or shared responsibility for

all of the family members. Togetherness for those families came through this team effort and support:

"For us, it's a team effort. We all take part in caring for her. Each and everyone in the family is involved, including my little kids. When they are at home, they keep company... play with her and talk to her. We won't let her [the MC] do things alone."

(Nuwan, 32y: Nephew, SC)

The secondary caregivers supported the main caregiver by becoming directly involved in caregiving activities or in other ways, such as providing material help or financial support. Direct or indirect support from family members appeared to reduce the workload of the main caregiver and also the burden of caregiving:

"I have asked my family to help me... my husband helps me a lot... He does things like shopping, laundry and cooking. He even attends to her personal care when I'm away." (Kumari, 47y: Daughter-in-law, MC)

Though in some cases extended family and wider social circles being overly critical and not seem to understand the situation, it appeared that in many families the family members who lived in the same household were most likely to support the main caregivers by being actively involved in caregiving activities. According to participants, the extended family and wider social circles also supported the family emotionally, financially, by providing transport when necessary, or by having some involvement in decision making:

"It was my husband who helped me to take care of my mother from the beginning. […] His little sister who lives the next door takes care of things if we are not home."

(Sujeewa, 55y: Daughter, MC)

"My mother, and especially my wife are my biggest strengths… Sometimes my kids come here and they help as they can... My friends are there to support me whenever I need help... They even cover me at work so I can attend to father's care. [...] Our neighbours are so encouraging… which kept me going on this journey for nearly five years." (Saman, 48y: Son, MC)

Some family members who were not involved in direct care commented that a close relationship enabled them to provide emotional support to the PwD and the main caregiver. This made them happy and also gave the main caregiver a break through them taking over caregiving responsibilities for a short period. The main caregivers greatly appreciated this social connectedness and emotional support alongside material help which they received from others:

"I am so happy when my daughter comes, because she spends most of her time with my sister [the PwD]. My sister is bubbly when she's around, tells stories about our childhood. We enjoy that a lot..." (Jayanthi, 66y: Sister, MC)

"My aunt visits so often. Two sisters spend time together chatting about their young days... So, I too have time for my other work. She looks more cheerful on such days. […] She also brings rice, coconuts and vegetables when she comes, which is very helpful." (Samanmali, 55y: Daughter, MC)

It also appeared that a sense of togetherness while engaging in day-to-day care activities brought a great sense of joy and pleasure to both caregiver and the PwD, as reflected in the following extract from a group interview:

Chamara: It's much fun to be with our Grandfather... What he says and does makes me laugh... My friends often visit me because they love spending time with him.

Rani: Yes! On such days I don't feel like I'm caring for a sick person. We are having a great time.

Another caregiver said:

"*We sometimes laughed at the things she says... We enjoyed her company." (Nelum, 67y: Sister, MC)*

However, some caregivers appeared to experience a lack of togetherness which they described as *'distancing'* or *'feeling strange'*:

"He is like a stranger to me; I mean not the person I knew... He's much distanced from us even though we live under the same roof. My father was a loving, caring person... I can't imagine how dementia has stolen him from us." (Sarah, 18y: Daughter, SC)

There were cases where other family members did not engage in caregiving and as such the main caregivers shouldered the majority of caregiving activities. These challenges will be presented in detail in Chapter Eight.

The caregiving role appeared to alter previous relationships between the PwD and the caregivers. They tended to gradually adopt new relationships with advancing illness and subsequent increase in care needs. Some reported positive changes where the caregiver and PwD have formed a closer, more personal relationship:

"She used to be my housemaid, but not anymore... We are like best friends now."

(Soma, 71y: Former employer, MC)

Some reported a shift in relationships, akin to role reversal where the parent has become more like the child. It appeared that the caregivers experienced some distance from each other as a result of their loved one's personality changes. For example, a daughter said she is like a *'babysitter'* to her mother:

"She is like a child. I take care of her like a babysitter now. I'm not glued to her. Just do the needful." (Samanmali, 55y: Daughter, MC)

Caregivers' acceptance of the caregiving role and their emotional reactions to behavioural and psychological symptoms of dementia (BPSD) were factors which caused changes to previous relationships and determined the nature of new relationships. Instead of experiencing a pleasant feeling of being united in the caregiving process some family members appeared to experience difficulties in continuing the care as a team. Their sense of togetherness, belongingness and support tended to weaken over time as the PwD's symptoms worsened.

"I don't feel like his daughter when I attend to most of his personal care. I feel like I'm his nurse. […] My daughters are afraid of his behaviour and stay away from him. Grandfather is a stranger to them now... Things are different, you know. My husband doesn't even notice him living with us anymore." (Niluka, 38y: Daughter, MC)

All the study participants appeared to experience the dynamic nature of togetherness between them and the PwD. This evolved throughout their caregiving journey. The following example illustrates how the relationships altered over time:

"Before she got this illness, she loved me like her own daughter... But [at the onset] she started yelling at me, said I steal her things... Those days, no one even visited our place... They were scared because she accused them too… of stealing. My life was like a roller-coaster! I loved her, but was so angry and frustrated too. […] However, we later found all of her LOST things... and the reason for her yelling [laugh]. Somehow, now she is not like that anymore. […] I feel like she is more attached to us now... All she wants is us being with her, all the time." (Kumari, 47y: Daughter-in-law, MC)

It also appeared that members of the same family experienced the distinction between togetherness and distance. The following example illustrates the different perspectives of Rani and other family members towards togetherness and distancing:

Mervin: It's good if I can stay with my daughter. I mean… as long as I live… I… haven't decided to leave yet... She is good... gives me food and drinks […] But I…, I feel alone. Sometimes I'm afraid... and lonely."

Rani: We chat during the day time. Sometimes he talks about the past... I like to hear those stories […] Some days my son cooks for us and he's like 'Seeya... come and help me, Come, cut onions for me. They sing songs while cooking, and have much fun together... I let him do such things.

Kithsiri: True... Now when I'm away it's good she has some companion... But the thing is, when she attends to his work all day, we have less and less family time... We can't go on a trip together... Ohh… [Angrily] Forget the trips, nowadays she hasn't got time to visit a relative even!

Mervin, the PwD, expressed his wish to live with the family as long as possible. The main caregiver and her son appeared to appreciate time with the PwD, but her husband, Kitshsiri, put forward a different perspective. According to Kithsiri, his wife's full-time commitment to caregiving created a distance between her and the rest of the family members. His reflections showed that greater togetherness between the main caregiver and the PwD has increased distance amongst the main caregiver and rest of the family members.

The majority of main caregivers, and those family members who spent a lot of time with the PwD, demonstrated stronger emotional bonding, empathy and understanding towards the behaviour of the PwD:

"I know when he's upset… and especially when he has the urge to wander. I think I understand him better than the others. Therefore, I don't get angry. I sometimes laugh at things and carry on my caregiving." (Rani, 52y: Daughter, MC)

In contrast, those who spent less time with the PwD demonstrated poor awareness and understanding of BPSD. Their reactions toward the PwD's behaviour and the main caregiver's role appeared to lack empathy (See Chapter Eight, Section 8.1.2 for examples).

Caregivers also reported their experiences of social connectedness. It appeared that this is influenced by the way others outside of the immediate family unit perceive illness and respond to BPSD. The majority of caregivers reported that neighbours responded positively towards the situation and connected with them by wishing a speedy recovery for the PwD, or by paying frequent visits to see the PwD and encouraging them to continue care and by giving support when needed:

"The folks in the village bring him home when he runs away. [...] one day a Tuk Tuk driver [taxi driver] found him and brought him home. […] Once he went missing for about a week or so. That time we found him with the support of the police."

(Premasiri, 71y: Brother, MC)

"Recently also [a friend] asked me about her… They used to meet so often at the temple. Since now she [the PwD] is not going there anymore [her friends] often visit her." (Jinadasa, 72y: Husband, MC)

However, in contrast, social isolation and lack of support was also reported by some caregivers. Some families reported that they were isolated or abandoned by the extended family, neighbours and the society as a result of having a family member with dementia (See examples in pages 261, 264-265 in Chapter Eight, Section 8.1.2).

However, some caregivers appeared to be disconnected from others by choice. They described continuous togetherness as enduring stress and an unpleasant experience and preferred to be disconnected from those who were the source of this stress despite their attempts at providing support:

"She [a relative] does my head in whenever she comes around. Once she suggested that I take my mother [to a witch doctor] which I didn't want to do. And she started telling me how to take care of my mother. I once asked her to mind her own business. I think I was rude to her... Finally, she ended up not visiting us anymore... which is good in a way... She wasn't helping at all." (Nirosha, 31y: Daughter, MC)

A few caregivers reported connectedness as an *'irritable', 'annoying'* and *'stressful'* experience; especially when they felt forced into becoming caregivers due to other

people's opinions. It appeared that these feelings were not related to the connectedness with the PwD, but with the other relatives and neighbours who were interfering with caregiving:

"Sometimes it's a trouble. Everyone is trying to help and they give us their opinions and expect us to do what they recommend. It is annoying when I have to please them all." (Sena, 68y: Husband, SC)

"Some neighbours, relatives even friends asked us to take him here and there. At the beginning I was ready to do whatever they say. But it became so stressful to me as I couldn't take care of him in the way I wanted. Finally, we decided to stop listening to them." (Saman, 48y: Son, MC)

There were cases where the PwD was looking for togetherness, while the caregivers were trying to avoid it. Disconnection can also be a coping mechanism. For example; some of the caregivers tended to avoid speaking with the PwD or reduced the time spent with them when the severity of dementia advanced. This appeared to disconnect them from the PwD both physically and emotionally. The following is an example from a group interview:

PwD: I feel frightened when she is not nearby. Feel incomplete. That's why I call her all the time

MC: I hate being with her all day. It makes me feel sick... All I need is some space; you know... I'm fed up fighting with her... I'm dying to go out and spend some time by myself... ALONE…

7.1.2 Communication

Communication is the second subtheme within the theme of connectedness. This includes verbal and non-verbal communication. It appeared that effective communication enhances the connectedness between the PwD, caregivers and also the wider social circle. Communication was an important determinant when coordinating care among the informal caregivers and the wider social circle.

Findings indicated that the main caregivers felt they could understand the PwD's gestures and facial expressions when there is a strong connectedness between them. This also improved the quality of caregiving, since these caregivers understood the nature of dementia, their caregiving role and the care needs of the PwD better than the others. Saman reported that spending considerable time with his father aided him in learning his father's behaviour patterns, emotions, feelings and care needs. He also highlighted the importance of non-verbal communication when providing care for his father:

"He can't talk to me but I understand his facial expressions… Even though he can't say it, I know what he needs... Having spending most of my days with him, I became an expert to hear what he doesn't say…" (Saman, 48y: Son, MC)

Effective communication between caregivers appeared to reduce caregivers' doubts and ambivalence when making care related decisions; which also increased the understanding between one another:

"It's my mother who looks after him when I'm at work, mostly in the mornings... I call her if I'm going to be late, so she can feed him till I come. I have taught her how to do that and we continue to do this together…" (Saman, 48y: Son, MC)

"I discussed her condition with my three children and also with my sisters... We discussed what to do… about her future and care arrangements. It was so helpful. We agreed to see a doctor as soon as possible. They all understood the seriousness of dementia and promised to help me to take care of her." (Jayanthi, 66y: Sister, MC)

The caregivers also reported that they communicated their grievances, stresses and care-related concerns with other family members, friends and sometimes with health care professionals in order to obtain advice, emotional support, and feelings of relief. According to most of the main caregivers, talking to someone who is knowledgeable, understanding and caring was an effective method of coping:

"Whenever I feel down, I call my sister. She listens to me… visits me often when I need to share my feelings. It's a big relief." (Rani, 55y: Daughter, MC)

"When I go to the dementia clinic I talk to [the consultant psychiatrist]. It makes me feel better." (Niluka, 38y: Daughter, MC)

"I often talk to other caregivers who meet at the clinic. Some are now my friends. We share our pain… When I listen to them, sometimes I feel like my situation is much better... Feel relieved." (Kumari, 47y: Daughter-in-law, MC)

A caregiver was grateful to the connectedness offered by the hospital staff through their communication, courtesy and emotional support when her husband was hospitalised:

"I couldn't take it any more when I see him like that, when I was crying the nurses and the doctors took my hand and accompanied me to their room. All are verr..y nice young people... They explained the situation to me and asked me not to cry. They said they will do every possible thing for him... Those words were so… kind and reassuring... I felt like I'm not alone." (Piyaseeli, 68y: Wife, SC)

Communicating the nature of dementia, as well as care needs, with their close social circles and wider community appeared important to informal caregivers. According to them it increased their level of support and reduced the perceived and actual caregiver burden over the longer term. Except for two families study participants reported that they have explained the situation in relation to dementia to friends, neighbours, taxi drivers and even professionals in order to obtain support in certain day-to-day activities related to the PwD:

"I've explained her situation to our neighbours. They also now keep eye on her... If they see she is walking towards the road, they inform me. [...] When I told the Bank manager about her condition, the bank manager said she doesn't need to come anymore; now I can get money from her account without taking her there." (Kumari, 47y: Daughter-in-law, MC)

"I've arranged [a taxi driver] to take her to the clinics when I'm not there... So I know she is safe with him." (Gayan, 50y: Son, MC)

"Some days they [neighbours] call me and tell me she is safe with them. We don't even know, she goes to their houses and spends all the day." (Chandrika, 60y: Daughter, MC)

However, a few caregivers appeared unwilling to communicate or *'let others know'* about the PwD's condition. Lack of dementia awareness, shame and stigma appeared to be the common barriers to effective communication (will discuss in detail in Chapter Eight, Section 8.1).

In the case of all families, communication failure and lack of meaningful communication seemed to cause gradual disconnection and distancing between the PwD and other family members. The connectedness between the PwD and caregivers seemed to gradually reduce when they fail to communicate effectively when severity of dementia increased over time:

"He has now forgotten us... He smiles and talks in a friendly manner with anyone, but can't recognise or recall who we are… He calls every one by the same name..."

(Chamara, 23y: Grandson, SC)

"We are losing him day by day… Physically he lives here but… but… his memory is fading away. It is very painful to see… I sometimes feel lonely, like I'm talking to myself. He's so quiet and I wonder whether he hears what I say at all. […] I feel like I'm getting much more distanced from him... like I'm with a stranger..." (Nimala, 64y: Wife, MC)

Some of the caregivers appeared to encourage the PwD to engage in verbal communication and active participation in day-to-day activities. They shared many examples of how they found alternative ways of communicating and staying connected with the PwD. For example, they talked with the PwD while engaging in daily routines around the house (e.g. cooking) or involved the PwD in activities such as playing games or singing:

"When I visit her, we spend time chatting. We usually chat while having a nice cup of tea... She opens up to me when we do so." (Dayani, 76y: Sister, SC)

"When I cook, I usually ask him to come and help me. He scrapes the coconut or cuts the vegetables for me... I like it. Earlier he didn't even look at the kitchen... [laugh] While cooking we talk about this and that..." (Niluka, 38y: Daughter, MC)

Some caregivers highlighted the importance of such interactions as they help the PwD to fulfil their emotional needs and to improve their psychological wellbeing. It also helps the caregivers to understand the PwD's care needs and concerns:

"I talk to him all the time... It doesn't matter even if he can't reply. But sometimes he smiles... and he blinks. That's enough! […] One day he suddenly called me 'Son', and cried. He remembered who I am. He called me 'Son' after like two years... It was an unforgettable moment. [Tears in his eyes]" (Saman, 48y: Son, MC)

However, caregivers tended to avoid communicating with the PwD towards the end-stage of dementia as they experienced stress and burden of caregiving. For example, many caregivers reported that they do not enjoy the recent conversations with the PwD because, repetitive questions from the PwD increased their distress:

"God… She asks the same question and I give the same answer repeatedly... It never ends. Does it? I feel a headache towards the end of the day... I try my best to avoid her." (Sujeewa, 55y: Daughter, MC)

One daughter said she does not talk with her father as it makes her feel '*sad*' and '*strange*':

"We used to sing and play dramas at home. It was father who wrote most of the scripts. I feel sad when I remember our past, the time I spent happily with my mother and father. I don't feel like talking to him much now, he is like a stranger to me…" (Sarah, 18y: Daughter, SC)

Saman reported that lack of verbal communication with his father was emotionally challenging, and also caused difficulties when providing care as his father can no longer verbally express his needs or feelings:

"It's killing me when he can't tell me whether he's hungry or not, whether he wants to go to the toilet or not. He can't remember who I am... That's pretty hurtful. It's killing me to see the tears in his eyes when he can't tell us what he feels. [Cries]" (Saman, 48y: Son, MC)

The nature of connectedness was influenced by the level of dementia awareness, beliefs and attitudes among caregivers, and the severity of BPSD. The caregiving situation and personal attributes of the caregivers were also significant contributors that determined the level of connectedness. It appeared that the relationships between the PwD, the main caregivers and other family members are dynamic and change constantly over time as the illness progresses, especially as the PwD undergoes behavioural and personality changes. Most of the caregivers reported that they experienced a negative caregiving relationship at the onset of dementia and it became more positive with acceptance of BPSD and the caregiving role. Some caregivers appeared to experience a negative relationship towards the end-stages of dementia, as a result of increased caregiver burden and lack of support. Therefore, connectedness seems a complex experience for caregivers and

it has a significant emotional impact on them. Issues and challenges related to connectedness will be described in detail in Chapter Eight.

7.2 Engagement

The theme of 'engagement' describes the meaning, purpose and experience of involvement and engagement in the process of caregiving. This theme consists of two subthemes: (a) motives for caregiving and (b) care models used by the caregivers.

7.2.1 Motives for engaging in caregiving

The caregivers reported different motives driving them to engage in care and to maintain enthusiasm for continuing their caregiving activities over a longer period. These motives include altruism (e.g. love, willingness and desire), reciprocation, commitment and sense of responsibility.

"I do it with love": altruism

The majority of the study participants described their caregiving experience as an 'altruistic activity'. The family caregivers appeared to engage in care with altruism which is described as a selfless concern of the caregiver for the wellbeing of the PwD. The study participants described the meaning of altruistic care as *'love towards their relative'*, *'willingness or desire to care'*, and *'a sense of joy or happiness'*. According to the majority, being the main caregiver is a decision made willingly with love and kindness. It appeared that the act of caregiving brought most of the family members a great sense of satisfaction when they did it willingly, with love and desire:

"It was my desire to take care of him. […] I love my father. I will treat him as best as I can. It's my choice and I don't care what I receive in return." (Rani, 52y: Daughter, MC)

"After all, he's my father... I'll take care of him till the last moment. […] Even though he lies on a bed like this today, my father is a king to me… I love my father... I do it with love." (Saman, 48y: Son, MC)

"It's my turn to pay back": reciprocation

Some of the caregivers reported engagement in care as an act of 'reciprocation'. They considered caregiving as an opportunity to show their gratitude towards the PwD. Children who provided care for their parents with dementia said they *'feel thankful'* to their parents and it is their chance *'to pay back'* for the unconditional love and sacrifices made by their parents; for example, for enriching their lives when they were young:

"*My father used to treat people well... He never ate before feeding us, you know… I am tremendously grateful to both my parents for who I am today... Now, since I'm in a position to look after him, this is the best way I could return the favour. It's my turn." (Rani, 52y: Daughter, MC)*

"*She is our mother… she took much pain to bring us all to this stage of life ... It wasn't easy to raise ten children without her husband... And now IT'S OUR TURN to look after her." (Kanthi, 52y: Daughter, SC)*

Some cared for the PwD to pay gratitude towards the kindness, love and support given by them during the most critical times of the caregiver's life:

"She was with me even after his [husband's] death and treated me like her own daughter... I am so thankful; she let me live in her house... This is the least I could do for her... It's my gratitude for her and my late husband." (Kumari, 47y: Daughter-in-law, MC)

"She took care of me and raised my children those days... And now it's my chance to return the favour for her. […] I'm so glad my children also remember that. They always tell me… 'Mother... We should do our best for her.' And that's what I'm doing right now." (Soma, 71y: Former employer, MC)

"I'm committed to care": commitment

The majority of informal caregivers who took part in the study were fully committed to caregiving despite their personal desires and other day-to-day activities. Some of them appeared to neglect their leisure, other work commitments, self-health and wellbeing, and even their personal milestones, such as marriage or education. They appeared to give priority to the caregiving needs of the PwD and continued to provide long-term care, despite the challenges such as caregiver distress. In this context, the caregivers described the commitment to care as '*devotion'*, *'keeping a promise*', '*sacrifice*' of caregivers' time for self, or *'giving priority'* to the PwD than their own lives:

"I am now mostly devoted for this [caregiving]. I left my job for her… I don't go on pilgrimages, not even to the temple, because, I don't like to leave her with someone else. I know they [friends and neighbours] would be happy to help us. But why should you trouble them when I'm immersed in care..." (Samanmali, 55y: Daughter, MC)

"I've sacrificed my leisure for her... We have a trip planned, but I won't join. […] When I took her in, I was determined to take care of her for the rest of my life... I still think the same way." (Nelum, 67y: Sister, MC)

"I promised my mother to take care of my sister as she had fits from her childhood. I didn't wish to get married because I was devoted to her. I gave my word, and I've kept that promise so far." (Sriya, 66y: Sister, MC)

However, it appeared that some caregivers were experiencing guilt despite their commitment to the care provided, due feeling a sense of failure:

"I brought her to my place to take care of her till her last breath... And I failed to do that... We both are old now and it's difficult for me. But… I feel guilty for sending her away." (Nelum, 67y: Sister, MC)

Some caregivers experienced guilt as they were failing to meet the needs of other family members as a result of their full-time commitment to the PwD:

"I have told my kids not to do anything extra because I can't leave their grandfather alone... I have asked them to look after themselves now… I used to help my kids with everything... But I can't do it anymore because of my father... I can't safeguard my kids." (Niluka, 38y: Daughter, MC)

"My kids are in the hostel and they visit me once in a while. I feel like I don't play fare with them as a mother. […] My son was crying and he begged to keep him with me last time he visited home. [Cry]" (Suneetha, 50y: Relative, MC)

"It's my duty": responsibility

Some of the informal caregivers identified the care engagement as their *'duty'* or *'responsibility'.* For some it was due to *'lack of choice',* and they commonly used the terms such as *'I had to'* or *'I should'* when expressing their views. When compared to others, the caregivers who had less support or were caring for a parent and had no other siblings, appeared to perceive caregiving as a duty or responsibility:

"That is my duty as a daughter. If I had a brother or sister at least I could share some responsibility, you know. But in my case, there's no such luck." (Niluka, 38y: Daughter, MC)

"I had no choice. I am the only child. I think it as my duty because they are my parents who gave birth to me… So, I'll do this as a duty… There's no bond... I mean I'm not glued on her... I think it as my responsibility..." (Samanmali, 55y: Daughter, MC)

In some families the main caregivers appeared to be the only person who was available or agreed to engage full-time in caregiving even though they had other siblings. They argued they had '*no choice but taking the responsibility*' of care:

"Some [of the siblings] said it's difficult with their jobs. Some were reluctant to keep him as they already had bad experience with him… One sister was too physically weak to take care of him, and my other sister didn't have the permission [from her spouse and children] to bring him home. […] No one wanted to keep him, he was a trouble… Then I agreed to take the responsibility to take care of him... I was the only one who agreed to take him in... I had to." (Rani, 52y: Daughter, MC)

7.2.2 Care models used by the caregivers

The subtheme of 'care models' describes caregivers' explanatory models (Weinman *et al.*, 1996) influenced their preferences of selecting treatments and interventions when managing dementia at home. Findings indicated that alternative (i.e. non-westernised or traditional) healing methods were common and still widely practised, as either first-line or sole treatments for dementia or as a complimentary treatment alongside western medical treatments. Among the twenty families interviewed, sixteen reported that they currently use or have previously used one or more alternative treatment methods. Table 7.1 provides a summary of the explanatory models which include treatment methods and interventions reportedly practiced by the caregivers during their caregiving journey.

Table 7.1: The treatment methods and interventions used by the caregivers

The treatment method	**Interventions or practices**
Western medicine	• Administer medication prescribed by the psychiatrists in the dementia clinic • Follow-up clinic visits
Ayurveda treatments Indigenous medicine	• Drink decoction and pills prepared by Ayurveda herbs • Local application of ointments, oil and massage therapy • Local application of herbal medicines grinded and applied as a paste over the head (*'Hisakudichchi'*) • Drink herbs chanted with mantra or magical formulas
Traditional healing practices	• Shanthikarma or Devil Dancing *('Bali Thovil'*) to please the supernatural powers or chase away the possessed spirits • Spells and mantra chanting to get protection from black magic, chase away evil spirits • Wear chanted threads, amulets, rings or charms • Cut lemons to expel evil eye, evil tongue, black magic and spells • Dashing coconuts on a holy stone at the God's temple or Kovil • Invoking the deities or the demons who caused illness, pray and do *'pooja'* (offerings) to them • Drink chanted water, lemon, king coconut water • Consult fortune tellers, *Pena* or *Anjanam* readers
Astrological Remedies	• Horoscope reading • Wear rings with charms or Gems to avoid influence of bad stars • Do rituals such as Bodhi-Pooja, worshiping Gods to reduce the effect from stars and request protection • Bahirawa pooja to protect the household from evil or dead spirits • Correct astrological misalignments in the house (usually rebuild certain sections in the house) • Burry chanted lemons, chilies in the home yard
Religious Practices	• Pirith chanting followed by wearing chanted threads in the neck and hand, and drinking holy water chanted by Pirith. • Worship and offerings to Bo tree (*'Bodhi pooja'*) • Sing *'Seth-Kawi',* a poem which sings after *Bodhi pooja* wishing protection and speedy recovery for PwD • Alms giving (*'Dhana'*) to Monks, elders, or animals • Abstain from sinful activities and engage in religious activities
Home Remedies	• Eat porridge made from '*Lunuwila*' plant (*Bacopa monnieri* – a herbal plant popular as 'the memory plant' in Sri Lanka) and '*Gotukola*' • Give over the counter drugs available in super market (e.g. vitamins and fish oils)

Practice of bio-medical model

The caregivers who took part in the study reported that they currently follow western medicine and /or traditional or alternative healing practices in the management of dementia in home-based care settings. Nineteen out of the twenty families were registered with the dementia clinic by the time of interview. Ten families reported they currently follow traditional or alternative treatment methods as either first-line or sole treatment for dementia or as a complementary treatment along with western medical treatments.

However, poor adherence to medication was reported by caregivers during home-based care. It was evident that many of the caregivers did not follow the recommended treatments or prescribed medications as advised by the health care professionals (HCP). In the early stages, this was reported as being due to their lack of awareness. In the later stages it was on purpose, as a result of their negative attitudes or burden experienced by the adverse effects of medication:

"When she was discharged [from the hospital] I thought now she's alright and I stopped her pills. I didn't know this before... That's why it was so late to start medication." (Kumari, 47y: Daughter-in-law, MC)

"We took medicine for him just once but did not continue. No one was sensible enough to continue treatments [smile]. We didn't see any improvement… So, we didn't think he needs further treatments." (Rani, 52y: Daughter, MC)

It appeared that some caregivers either did not understand or did not accept the degenerative nature of the condition even at the advanced stages of the illness (discussed in Chapter Six, Section 6.1.3, pages 176-180), which then had

implications for their expectations of health care. For example, the caregivers tended to lose interest in continued clinic attendance when the severity of dementia increased, as they no longer trusted the health care system to *'cure the condition'* or *'help them'*. Financial constraints affecting transport and affordability of medication then presented additional challenges:

"*She is not getting any better, is she? Spending money on her medication is a waste. She doesn't even take them willingly. We didn't want to bother her with too much travelling and unnecessary medications. So, we quit.*" *(Chandrika, 60y: Daughter, MC)*

Some caregivers appeared to think that without drugs the PwD could have a better quality of life and they therefore discontinued medications and stopped attending the clinics, as this improved day-time activeness and eliminated the side effects caused by the medication:

"I don't give all the pills as prescribed... I don't know whether my father will die tomorrow or day after... But I need him to be alive... Pills make him weak and sleepy... I understand how much he can tolerate. The doctor told me to increase the dose, but I decided not to." (Niluka, 38y: Daughter, MC)

"Pills made her sleepy during the day-time and she happened to fall several times. I quit giving her pills." (Chandrika, 60y: Daughter, MC)

It also appeared that family members were making care-related decisions based on weighing up the cost-benefit in relation to their own circumstances. For example, some reported that they did not see the medication as having enough benefit when compared with the cost and time needed to obtain it. Caregivers

tended to deviate from the medical care model and embraced alternative treatments, such as traditional or religious remedies instead, especially when there was no visible therapeutic effect from western medicine, only side effects:

"The [dementia] clinic was useless... Pills only made her sleep even during the day... We saw no improvement. Now we don't go to any clinic. Instead, we did several Pooja." (Gayan, 50y: Son, MC)

"There was no improvement... and it was such a waste of money and time on so-called expensive medication and for transport... Finally, we decided to try other things as well." (Sena, 72y: Husband, SC)

Practice of Ayurveda model

Ayurveda treatments and indigenous medicine or '*Deshiya Chikitsa*' also seemed to be practiced by some of the caregivers. A caregiver said they chose Ayurveda medicine as the first line treatment prior to starting western medicine:

"We did Ayurveda medicine when we were at [village]. He was asked to wear a hisakudichchi [a local application prepared by herbs to apply on head]." (Nimala, 64y: Wife, MC)

"The [indigenous doctor] gave us some kind of pills. He told me that the pills were from India… He also gave us some kind of oil to apply on her head and shoulders. […] He asked us to give her 18 doses of decoction which we somehow managed." (Sena, 72y: Husband, SC)

However, it was evident the Ayurveda therapies were difficult to continue over the longer term due to scarcity of herbs and ingredients, expensiveness of the treatments, and practical difficulties of traveling with the PwD or reaching the

popular Ayurveda doctors. Therefore, the caregivers tended to give up on these treatments over time:

"His 'hisakudichchi' was prepared using a pulp of herbal leaves [such as Alovera, Kohomba and Kumbuk]. We were instructed [by an Ayurveda doctor] to continue that for six months. However, we can't do that here in town. Preparation is difficult, I can't be bothered to make the pulp from all those leaves. Another thing... it's difficult to find those leaves here." (Nimala, 64y: Wife, MC)

Practice of other care models influenced by religion and culture

Chapter Six, Section 6.2.2 discussed how caregivers' perceptions of the causes of dementia were influenced by their cultural and religious beliefs. Similarly, these religious and cultural views, myths, faith and beliefs among the caregivers appeared to have a strong influence when defining the meaning of caregiving and when selecting care models to manage the condition.

The religious and cultural beliefs and related treatments or healing practices were considered as an important part of caregiving in the study context. It appeared that the caregivers often adopted religious or spiritual model, super-natural model or social model in addition to (or along with) the bio-medical model (Weinman *et al.*, 1996).

Among the religious practices there were *Bodhi Pooja*, singing '*Seth Kavi*', alms giving (*Dhana*) and P*irith* chanting (See Table 7.1, page 215). *Bodhi Pooja* is a religious ritual of worshiping the Bo tree in the temple for three to seven or even more consecutive days, with offering flowers, walking around and watering the tree. *Seth Kavi* are types of religious poems, mostly sung by Buddhists during their

'Apala' or difficult times. The purpose of singing '*Seth Kavi*' was to wish PwD a speedy recovery, and request blessings and protection from the Gods in the temple and the Gods of the astrological planets:

"We held a Pirith chanting ceremony at home and did many religious activities to wish him speedy recovery." (Niluka, 38y: Daughter, MC)

"She is going through a very bad 'Apala' time. We chanted Pirith, sang Seth Kavi and did a Bodhi Pooja. She is wearing these chanted threads around her neck and wrist for protection." (Sena, 72y: Husband, SC)

Caregivers appeared to believe that the PwD is protected from negative astrological influences and evil spirits by the power of *Pirith* chanting, *Poojas* and charms. Therefore, these practices were considered an important part of caregiving:

"I chanted [some Pirith] 1000 times, Rathana sutra was chanted 21 times; another Gatha… 108 times. Both my mother and the house is now protected from the evil by this. […] Her appetite increased after I gave her those lemons [chanted by Pirith]." (Samanmali, 55y: Daughter, MC)

Some caregivers reported that they tended to obtain frequent horoscope checks and astrological readings to determine the influence of *'bad stars'* before starting any treatment or sometimes during ongoing treatments. They believed the efficacy of medical treatments can be reduced if there is a bad planetary positioning in the PwD's destiny. They also strictly adhered to the guidance provided by their astrologers, or witch doctors, to remedy the situation. They also argued that

religious and astrological remedies can improve the therapeutic effects of other treatment methods, including western medical treatments:

"I checked her horoscope... All the treatments were planned according to that… I checked it from two to three places as I couldn't rely on just one reading." (Sena, 72y: Husband, SC)

"A monk told me this house is not good for living... Not only mother's life, it will also ruin all our lives. So, I immediately changed the plan and rebuilt it according to his guidance." (Kelum, 31y: Son, SC)

Devil dancing ('*Thovil*') and '*Shanthikarma*' were commonly practiced to treat the perceived super-natural causes such as possession. The purpose of this was to please the spirits by offerings, and sometimes to chase away the evil from the PwD's mind:

We invited a witch doctor to our home... and did a Thovil; at the end he cut lemons to protect us from evil... and gave us six spelled lemons... We buried four of them in the four corners of our house. The rest of the lemons were for the patient to drink... We have also planned to do a Shanthikarma." (Gayan, 50y: Son, MC)

Some of the caregivers reported they made offerings called '*Deva Pooja*' to the God (usually fruits and sweets), made vows and prayed for blessings, followed on some occasions by dashing coconuts in order to wish their relative a speedy recovery and protection from the Gods:

"Those days I did many Pooja to the [God] wishing her speedy recovery... I've been to every temple, every Kovil..." (Kumari, 47y: Daughter-in-law, MC)

Some of the healing methods involved a combination of cultural and religious care models (e.g. *Thovil* and *Shanthikarma*). Most of these healing methods included traditional dancing rituals, charms, mantras and '*Pirith*' chanting which invoke the noble qualities of Lord Buddha:

"That was a mysterious thing [like voodoo]. The witch doctor gave us an amulet chanted with Abhisambidana Piritha [a powerful Pirith chanted by Lord Buddha] to wear... It could protect us from evil." (Nimala, 64y: Wife, MC)

However, some caregivers argued that most of the cultural and super-natural models were less effective and influential than they expected and those remedies *'made things worse'.* For example, Kelum explained that despite the money spent to correct the astrological misalignments in their house, the PwD (Kelum's mother) was experiencing greater difficulties adapting to the changes in the house due to her memory loss. This situation caused Kelum greater distress:

"We did a Bhahirawa Pooja. We even changed the architecture of this house. […] New changes to the house made things worse… My mother became so disoriented after the changes. I wasted lots of money on this house." (Kelum, 31y: Son, SC)

Engaging in these religious and traditional interventions appeared to provide a coping mechanism and spiritual healing practice for most of the caregivers. Therefore, they tended to continue practicing these alternative care models even after they became more aware of dementia and its nature:

"Pirith chanting makes me feel good... I always do religious activities as it gives me a relief." (Samanmali, 55y: Daughter, MC)

7.3 Control

The majority of the study participants reported that they provide 'tender loving care' for the PwD. However, some of the caregivers reported that there were situations where they treated (or continued to treat) the PwD harshly and used power or force to control, restrain or limit certain activities or irritable behaviours, with or without an intention to punish the PwD. Negative reinforcements, or punishments, used by the caregivers included shouting at them, locking them inside the house or in a room, verbal threatening to send them away from the home or physical restraint. The theme of control highlights these negative practices of caregiving.

In most cases, the caregivers reported that they often make decisions on behalf of the PwD, regarding their care arrangements or treatments, which they see as being in the PwD's best interests. It appeared that the caregivers decided the PwD may not have the capacity to make decisions due to their forgetfulness, BPSD, dependency and their physical disabilities:

"She can't remember her meal times if I didn't give it to her. She can't remember whether she had her meal or not... I have to decide what she eats but she sometimes refuses." (Samanmali, 55y: Daughter, MC)

"It was difficult to take her to the clinic. She denied and kept refusing. We had to lie and pretend it was us who needed to see the doctor; not her. Then she joined us." (Edwin, 68 y: Brother-in-law, SC)

Some caregivers reported that they used force to control the behaviour of the PwD (mostly wandering) as they felt responsible for their safety or due to fear and

anxiety caused by the perceived burden of care. The caregivers appeared to control any activity or behaviour that might lead to injury; for example, PwD's attempts to get involved in household activities:

"She wants to cook, but I don't allow her to play with fire. She is bit angry about it." (Samanmali, 55y: Daughter, MC)

In some cases, caregivers had completely restrained the PwD's freedom:

"We stopped his bike riding completely since last year... He now can't find the way home. […] He happened to cut his finger on a blade, so I won't let him use sharp items such as knives or razers anymore." (Nimala, 64y: Wife, MC)

"I don't let her go out. I lock the doors and keep her inside the house. When I go out, I lock her in her room. For her safety, you know." (Soma, 71y: Former Employer, MC)

However, some of the caregivers appeared to encourage a degree of independence and provided a limited range of freedom to the PwD:

"We let her do simple activities, like serving her self during the meal time... She wastes lots of food, but we don't say a thing. […] She selects her own clothes, but we give her options." (Nelum, 67y: Sister, MC)

Five of the PwD who actively took part in the interviews appeared to be worried about being dependent and concerned that they were *'no more useful to the family'* and *'living under someone else's control'*:

"*I wish I could do a job. Those days I earned so well and I had enough money. Look at me now. I can't just eat from what my son-in-law earns. Can I?" (Mervin, 88y: PwD)*

"I should be taking care of my family; instead they are taking care of me. I feel like I'm a trouble…" (Basil, 68y: PwD)

Based on what the PwD said, it also appeared that over time the caregivers tended to forget their life before dementia and treated them with less respect and empathy. It appeared that PwD's autonomy, freedom and independence were restricted and not considered as important by their caregivers. For example, one PwD said:

"She is so bossy... Always telling me what to do... She is my daughter and now she tells me how to behave. It's not right... Is it? That's why I am angry at her... I'm not a child." (Rosalin, 83y: PwD)

Some caregivers accepted that they paid less attention and respect to the PwD's age, free will, autonomy, emotional and physical needs when making most of day-to-day decisions. It appeared that the PwD's cognitive abilities or freedom to make simple choices were not generally taken in to consideration:

"I can't be bothered to take her to the church… I can't send her alone either. I am Buddhist and I made her worship when I worship Lord Buddha each evening." (A Brother-in-law: SC)

"We give him everything… food and clothes… All he has to do is eat and sleep. Isn't that enough for an old man like him? [sounds angry] It's difficult to satisfy him." (A Son-in-law: SC)

It also appeared that the attempts of control resulted anger. Caregivers projected their anger on the PwD or the other family members; or sometimes the displacement of anger was directed towards themselves:

"She shouts at Nelum [MC]. And then Nelum shouts back at her. I'm like 'we can't have two psychos in this house. So, you [Nelum] should act like a saint.' [laugh] She shouts at me when she comes to end of her tether." (Edwin, 68 y: Brother-in-Law, SC)

"My anger and frustration are often displaced on my father. Sometimes I shout at my children or husband. If I go on like this, I will soon ruin my family life too. " (Niluka, 38y: Daughter, MC)

One caregiver tried to control what she perceived to be her mother's repetitive and irritable talkativeness throughout the interview. She did not approve of this behaviour and shouted at the PwD, asking to behave:

"MOTHER! How many times I've asked you to not to speak nonsense. [towards me] Throughout the day she enunciates 'ala... hula', a meaningless phrase! I don't know what that means... I've asked her to meditate instead of talking nuisance." (A daughter: MC)

Some caregivers reported that they misused prescribed medicine in order to control the irritable behaviours of the PwD. For example, a few caregivers said that they over-medicated the PwD with sedatives as it increased sleepiness during the day time and reduced the PwD's wandering, which gave the caregivers a break from needing to be constantly vigilant:

"When he troubled me too much, I gave him an additional pill or two… That makes him sleep longer. I used to do that quite a lot." (A daughter: MC)

"Father screams throughout the night... So, my mother couldn't get quality sleep for days. I was afraid that she would fall sick too... I explained the situation to the doctor and requested some sleeping tablets. He asked me to give a half tablet but it didn't work for him. So, the next day onwards I gave him the whole tablet..." (A son: MC)

It was also reported that PwD were sometimes *'ill-treated*' and *'punished'* by the caregivers due to their anger, frustration and caregiver distress. Reported punishments included threatening, shouting, locking the PwD inside the house and in one incident, beating with a cane:

"One day I brought a rope and told her 'If you speak any filthy word hereafter, I will tie you up to this tree'." (A brother-in-law: SC)

When he troubles too much we usually say, 'We'll send you to an elderly home if you don't behave well. We can't keep you here.' […] My elder brother is very strict. He used to lock him up when father was screaming." (A daughter: MC)

It appeared that the caregivers who used such force towards the PwD did not think that their actions might cause physical or psychological harm to the PwD, and insisted that their *'intention was good*'. For example, some caregivers argued that they were concerned about the safety, health and wellbeing of the PwD and used force to control their BPSD:

"I can't take the risk of losing him again. He ran away two times. No matter how loud he screams; I lock him in the room. What if he gets hit by a vehicle while wandering?" (A daughter: MC)

"When she refuses a meal we usually tie her to the chair and then push the food balls in to her throat. She has to eat to live. There's no other way we make her eat." (A husband: SC)

In the above extracts it appears that the caregivers felt that the use of force to control the PwD was necessary and unavoidable due to their demands, stubbornness and uncooperativeness. Caregivers also appeared to misunderstand the BPSD and think that the PwD was trying to escape from household responsibilities, misbehaving or acting deliberately, leading them to express anger and frustration towards the PwD. For example, a main caregiver said his wife [the PwD] was deliberately trying to insult him or make things difficult for him. His anger towards his wife led to him physically abusing her:

Family member 1: He always forces her to eat even when she has no desire. Certain foods aren't even good for her diabetes. He's like, 'you have to eat this... and that…' So controlling.

Family member 2: I'm a grumpy old man. [Angrily] I can't dance according to her tune, can I? She should learn a lesson not to make me angry... Once I hit her with a cane as she denied the meal, I cooked for her. I hit her... Hit and hit her till she had enough. I was so angry...

Evidence of physical violence towards the PwD were also reported in some families:

"There have been uneasy occasions... Occasions where my husband had beaten father... Father had also beaten him back... My father used to threaten us, saying he will break us apart… So, my husband is angry at my father…" (A daughter: MC)

In some cases, the caregivers said, they were *'bullied'* or *'abused'* by the PwD, and that relatives and neighbours – who were presumably unaware or unaccepting of the person's dementia – sided with the PwD during arguments:

"I was abused by her [the PwD]. She labelled me as a thief. Relatives and some neighbours also believed that I really stole her belongings. She quarrelled with me and accused me saying I steal her things. She troubled me so much." (Kumari, 47y: Daughter-in-law, MC)

Some caregivers were beaten by the PwD as a result of trying to dominate and control them. Two daughters from different families reported that their parent became agitated and aggressive, resulting in them being physically violent towards the main caregiver:

"I can't control her when she's mad at me... She yells, sometimes even beats me. She slapped me the other day when I asked her not to visit [a neighbour]." (A daughter: MC)

"He [PwD] started beating me... I even made a complaint with the police. […] My throat was once swollen from a hit I received. He's so strong and I couldn't really stop him." (A daughter: MC)

However, in most of the cases the caregivers appeared to experience guilt for using force to control the PwD's behaviour, despite their good intentions such as safety and wellbeing of the PwD.

"I feel sad for giving him too many pills. I don't do it anymore." (A daughter: MC)

"He becomes very irritable during nights… So, I always tie him to the bed... for his safety... I hate doing that… but… I have to. [Cry] Every time I do this I beg for forgiveness. What a sin! It's killing me to tie him like an animal every night... I am crying and blaming myself for doing this... But I can't take the risk of him falling or injuring himself. At least my intentions were good, right? God may forgive my sins as I'm doing it for his own wellbeing." (Saman, 48y: Son, MC)

7.4 Awakening

The theme of 'awakening' describes the process of growth and empowerment caregivers experienced through increased dementia awareness, understanding and acceptance of their caregiving role or identity of 'caregiving career'. Two subthemes emerged: (a) learning, and (b) spiritual awakening.

7.4.1 Learning

As revealed in the Chapter Six, dementia awareness among the majority of the study participants was at a lower level at the beginning of their journey as dementia caregivers. However, the caregivers tended to learn through their caregiving experiences and living with the PwD. This includes learning about the nature of dementia, its signs and symptoms, caregiving skills and life skills such as anger management and coping skills. It appeared that the learning aided them to transform their myths, false beliefs and negative attitudes. Learning also increased the understanding and level of commitment towards caregiving activities:

"After your first visit [Individual and group interviews were carried out in two different days] my husband changed the way he treated my father. I think he started

believing about the illness. His awakening is fabulous! I'm so relieved now." (Rani, 52y: Daughter, MC)

Caregivers argued that their confidence to provide care increased over time through learning and experience. According to most of them, their anticipated fears and uncertainties about the illness and what the future held for the PwD tended to disappear when the caregivers actually faced crisis situations and realised that they were in fact able to cope with these situations. They accepted the nature of the illness and learned to be prepared to face future circumstances. A main caregiver described her learning experience as follows:

"At first I thought I won't be able to do this. To be frank I was thinking how to face this alone. What should I do in an emergency, like if she had a fall? […] It was at the beginning... But when I got used to this, those negative feelings eventually faded away and I felt like I'm strong enough to face anything. With time I automatically started thinking like that [I can manage things]. To tell you how, she fell several times. When that actually happened, I somehow faced the situation… I got panicked... Took her to the hospital... Searched herbs... I can go on. [long pause] Now there's nothing new to think, I know exactly what to do by experience [Smiles]." (Samanmali, 55y: Daughter, MC)

The caregivers who did not have any previous exposure or skills training to provide home-based care for a PwD at the start reported that they felt helpless at the beginning but gradually learned the skills needed to provide this:

"There were situations that I cried without knowing what to do... I hadn't had any experience at the beginning. Like… to bath him or turn him... I learnt them later when I was watching my father [being cared for] at the hospital. We had to get support from a paid caregiver. […] I was watching how he offered the bed pan, how he changed father's Sarong, how he gave the back massage, and applied cologne. Now I do the same without any problem... I learned things by watching." (Saman, 48y: Son, MC)

In addition, caregivers appeared to learn tolerance, patience and coping with emotional reactions to PwD's BPSD alongside the caregiving skills:

"One would need much patience to deal with such occasions [arguments with the PwD]. I think I've learned to be calm and tolerate her behaviour over these years." (Samanmali, 55y: Daughter, MC)

"I was mad at him those days... But now I've changed... I don't get angry at his behaviour, instead I laugh at them. Now I have that ability… Even my children sometimes say, 'Mother, thanks to Grandfather you have changed a lot'. Isn't that good?" (Niluka, 38y: Daughter, MC)

Some of the caregivers appeared to share their stories with others and learn from one another's experience:

"I normally talk to other women who visit the clinic. We learn from each other. When listening to their stories I feel my situation is far better. My mother doesn't trouble me that much..." (Kumari, 47y: Daughter-in-law, MC)

7.4.2 Spiritual awakening

Another important aspect of awakening was 'spiritual awakening' which occurred through the transformation of self by understanding of the impermanent nature of life. In chapter Six I described how the religious concepts such as *Karma, Pin, Paw,* God's wish and reincarnation have influenced illness perception and identification of the causes of dementia. This subtheme presents findings on how religion (mainly Buddhism) influenced the caregivers' views and perceptions of caregiving. An overwhelming majority of the caregivers reported that they engage in caregiving, because it is the 'living according to *Dhamma' or* Lord Buddha's teaching:

"My Lord Buddha preached, 'caring for the sick is the same as caring for me!' I have made my mind thinking of Dhamma facts. I follow the noble path [the noble eightfold path] shown by my Lord Buddha..." (Samanmali, 55y: Daughter, MC)

Some of the family caregivers who cared for older adults with end-stage dementia said they thought that their relative was in pain and death would be a relief to them as it will free them from suffering and end the *'Karma'* for their current life:

"Not that I cushioned the blow of my burden. I love my father. But at times I feel like, I... I... wish he dies soon. He suffers a lot and I just can't watch him being like this... Death at least will mark the end of his suffering. I mean both of us will be relieved from this Karma." (A Daughter: MC)

Through caregiving they felt they had experienced the actual meaning of Lord Buddha's discovery of the four noble truths (the foundation of Buddhism). The four noble truths are suffering or '*dukkha*' (e.g. birth, ageing, sickness, death, unpleasant things such as separation from loved ones or not receiving what one desired),

causes for suffering (e.g. clinging, desires, craving for pleasure, existence), cessation of suffering and the path that leads to the cessation of suffering (the noble eightfold path):

"This is what Lord Buddha taught us… From birth to death life is full of suffering. My mother is suffering because of ageing and sickness. I'm suffering because of her… I mean it's painful to see her struggles to live... There's no other way to find the freedom [nirvana] rather than following Lord Buddha… You can do whatever you want; but, if you looking for freedom, you need to walk the path he showed us…"

(Samanmali, 55y: Daughter, MC)

Some caregivers related the concept of *'dukkha',* or suffering, as a shared suffering for previous *Karma* among the PwD, family members and even relatives who were involved in caregiving:

"*Now, mother is suffering... not only her, we too are suffering... if something like this happened to us, one day our children will suffer the same...This must be some sin we all had committed together in a previous life, and we all have to go through this pain in this life." (Neela, 62y: Daughter, SC)*

Some experienced tension between positive outcomes and experiences of suffering:

"Caregiving experience changed my vision for this life, it changed the way I used to think, it made me an entirely different person… I am adapting to this life… and trying to see the bright side even though I'm suffering." (Niluka, 38y: Daughter, MC)

The noble path to relieve suffering is learning to let go of the greediness and desires and to finally attain *'nirvana'*. Lord Buddha called the final outcome of

understanding these four universal truths attainment of salvation or *'nirvana'* - achieving freedom from the cycle of rebirth by stopping the flow of *Karma* and ongoing existence (Obeysekere, 2002). It appeared that the caregivers accepted the nature of life; that is that change, destruction and suffering are inevitable. Many of the Buddhist caregivers said they learned in practice what Lord Buddha taught about impermanence, suffering and dissatisfaction:

"*Most of our suffering is due to greediness, because we crave and we assume things are permanent when it is really impermanent. Even our-selves. We are so much attached to things, and we worry when things change... Once we realise nothing is permanent and it's easy to let things go... and we achieve true happiness and end suffering... It was such a pain to look at my mother, and see her suffering... I was so worried... But over time... I changed my perceptions of the world... I let her go… I'm no longer attached to her like in the early days. Being her caregiver, I gradually learned that nothing is permanent. Dissatisfaction is suffering. I have done what I could do for her... I'm truly happy. My life changed after I became her caregiver."*

(Kanthi, 52y: Daughter, SC)

"It was difficult at the beginning. Everything was painful. But with time we learned how to let things go and alleviate suffering… This is what Lord Buddha taught us... realisation of impermanence." (Samanmali, 55y: Daughter, MC)

It seems the understanding of inevitability brought comfort to the caregivers, helped them with coming into terms with it and learning to cope using a 'Buddhist way of thinking'. They used Buddhist teaching of impermanence and uncertainty of life as a coping mechanism rather than worrying about the deteriorating nature of dementia:

"I have made my mind thinking of Dhamma facts. Or else it would have been difficult for me to be with her [illness]. I managed to make my mind to some extent... Not much I mean... a little improvement." (Samanmali, 55y: Daughter, MC)

"I have understood and live according to Lord Buddha's teaching [of impermanence]. This life is so uncertain... It's applies to her [the PwD] too... I mean to anyone." (Dayani, 76y: Sister, SC)

The concept of 'learning to let go' also appeared to be an effective coping mechanism which minimised the perceived burden of care. The family members who cared for a person with end-stage dementia (five caregivers) said that they tried their best to cure their loved one in the beginning. However, towards the final stages of dementia they understood the nature of illness, changed their attitudes towards treatments and improving quality of life, as well as the care provided:

"I tried my best to find a permanent cure for this. did every possible thing. But I learned finally you don't have a cure for dementia. […] All I need now is to do my best to care for him; to keep him happy as long as he's alive." (Saman, 48y: Son, MC)

However, it appeared that the caregiving experience had a significant impact on caregivers' lives as they underwent permanent changes and adaptations in lifestyles. The caregivers appeared to be awakened spiritually by their exposure to caregiving:

"Till my mother develop dementia I didn't think like this... But now I think differently. I used to be a materialistic person. But not anymore... Property and money seems so fake and worthless to me now... Things turned upside down within these three years..." (Neela, 62y: Daughter, SC)

"I used to work like a horse… was never available for my family. Now look at my mother… She was fighting with me and my father for money. She doesn't even know what she's doing anymore. I want to enjoy the rest of my life with my kids and leave good memories. Life is too short. I'm determined to enjoy it." (A Son: MC)

7.5 Chapter summary

The meaning, practices and purpose of caregiving has been explored through four themes: connectedness, engagement, control and awakening. In general, for all the study participants the journey of caregiving was a combination of both positive and negative experiences. The themes of connectedness, engagement and 'awakening' predominantly represented the positive experiences of caregiving, while the theme of control represented the negative aspects. The meaning, practices and purpose of caregiving appeared to change over time. Caregivers'preferences for explanatory/ care models, treatment methods and caregiving styles also showed progressive changes.

With increased dementia awareness and caregivers' experiences gained through the very act of caregiving and/ or living with the PwD, the caregivers underwent a transformation of their thoughts, beliefs, attitudes and personal values. They also tended to find new meanings in caregiving, as well as in their own lives, through integrating the consequences of dementia into them. For example, the theme of awakening discussed a series of transitions and transformation of the self. Acceptance of 'caregiving career' (Nikzad-terhune, 2011), commitment to caregiving and learning to cope was demonstrated through a Buddhist way of thinking. Some family members appeared to accept and adjust well to their

'caregiving career', demonstrated good coping and less caregiver distress by moving with the continuous changes of the PwD and learning about the condition.

Evidence suggests that the positive experiences outweigh the negatives. The connectedness of the PwD and caregivers appeared much more meaningful and important to the PwD in terms of coping with their fear, confusion and dependency. Positive inputs, such as encouragement and support from the secondary caregivers and others, seemed to provide a more positive caregiving experience to the main caregivers and reduced their distress. When the caregivers were immersed in caregiving they appeared to understand and accept the gravity and responsibility of the tasks involved, and also perceived happiness and satisfaction.

However, in few cases, the main caregivers reported that over involvement and engagement of other family members and outsiders in care caused disputes, tensions and increased their perceived or actual burden of care. Blame appeared to be one of the major concerns when attributing the meaning of caregiving (e.g. place the blame on PwD and others during the caregiving activities, engagement in care as a result of avoiding getting blamed). There were discrepancies between PwD and caregivers in perceptions of the care needs and caregiving. There was evidence of caregivers restricting PwD's freedom and autonomy (in terms of safety concerns), showing less respect towards PwD's identity, personal values and concerns when informing care-related decision making, and also incidents of using force to control BPSD and physical and emotional abuse. The negative meanings and experiences caused distress despite the caregivers adapting to changing circumstances. The next chapter will present findings relating to caregivers' concerns, issues and challenges.

Chapter Eight
Caregivers' concerns, issues and challenges

The previous two chapters presented findings on the meaning of dementia and caregivers' experience of dementia caregiving. This chapter presents the third super-ordinate theme that emerged from the analysis: 'caregivers' concerns, issues and challenges' in relation to caregiving and living with a PwD. The super-ordinate theme consists of three themes: (1) Caregiver burden, (2) Service gaps within the current health care system and (3) Caregivers' suggestions to address the issues and challenges experienced.

8.1 Caregiver burden

The theme of 'caregiver burden' explores the negative experiences, which includes physical, emotional and financial strains of caregivers over the course of their journey. Findings will be presented in relation to two subthemes: (a) burden related to caregiving activities and (b) the broader sense of burden driven by the family and social context. Burden of care was perceived as an individual or group experience among the caregivers.

The findings described below are based mainly on the interview data, but are supplemented by the responses to Zarit Burden Interview (ZBI) (See Appendix 13, page 418). Table 8.1 (page 240) summarises the level of burden reported by the main caregivers on the ZBI. According to ZBI scores 75 percent (n=15) of the main caregivers experienced some form of caregiver burden (i.e. mild, moderate or severe) whereas 25% reported they do not experience a burden. Ten main

caregivers experienced mild to moderate burden, four experienced moderate to severe burden and only one reported experiencing severe burden. These scores will provide context and comparison for the discussion of the interview data in relation to the identified themes.

Table 8.1: Level of burden experienced by the main caregivers according to ZBI scores

Level of Burden	Number of participants N %
No burden	05 (25)
Mild – moderate	10 (50)
Moderate – severe	04 (20)
Severe	01 (05)

** The ZBI scores are interpreted as: 0 -21 little or no burden, 21 – 40 mild to moderate burden, 41 – 60 moderate to severe burden, 61 – 88 severe burden (Zarit, *et al.*, 1986)

8.1.1 Burden related to caregiving activities

According to the findings presented in Chapter Seven, the majority of caregivers perceived caregiving as a positive experience, despite some degree of distress and burden related to actual caregiving activities. They referred their sense of burden as inability to care, exhaustion or increased workload. Some appeared to experience an emotional burden in terms of helplessness, fear, anger, frustration and guilt.

"I can't do it anymore": Age, gender and physical inabilities of the caregivers

Eight main caregivers, who were spouses or siblings of PwD, reported that they often experienced a significant burden of care due to their old age, ill-health and physical weaknesses, which limited their capacity to engage in day-to-day caregiving activities. With two exceptions, all of the main caregivers (18) were aged

45 or older, among them nine were over 60. They stated that their most challenging caregiving activities included attending to the PwD's personal care and activities of daily living and lifting and transferring the PwD; for example, moving from chair to bed or walking them to the toilet. A high sense of burden was reported when the severity of dementia increased, if the PwD was bedridden, or he/ she was completely dependent on care:

"I am old just like him. With my back pain I can't assist him to the toilet or walk him back to the bed. When my son is not around, I feel helpless. […] I'm afraid to feed him when he lies [supine] on the bed, I can't take him to the chair alone... He's heavy..."

(Piyaseeli, 68y: Wife, SC, ZBI score =47)

"I am not in a position to take care of her now. I can't take her to the clinic. I hate walking, taking the bus... and waiting at clinics. […] I feel tired and inactive with my illness [renal failure]." (Jinadasa, 72y: Husband, MC, ZBI score =36)

Most caregivers reported that caregiving for the PwD was challenging when PwD were less cooperative. BPSD such as poor compliance with eating and treatments, increased dependency, wandering, stubbornness and aggression from the PwD were just some of the challenges the caregivers faced, especially when they were not confident and inexperienced in caring:

"We need to shower her, need to feed her, need to assist her in going to the toilet, need to comb her hair... she doesn't do any of the work... We have to do everything for her." (Kumari, 47y: Daughter-in-law, MC, ZBI Score =18)

"She is such a burden... Both my wife and I are now so sick of this... We can't be bothered to find her whenever she runs away from home." (Lal, 62y: Son-in-law, SC, ZBI Score =48)

There appear to be differences between the burden reflected in the ZBI scores and the burden being discussed in interviews. The above quotations suggest severe burden experienced by the caregivers but their ZBI scores indicated mild or moderate burden.

One person with mild dementia, who also had diabetes was self-administering insulin injections alone. The main caregiver was worried that the PwD stubbornly persisted in doing this, because of the associated risks:

"She [the PwD] is the one who takes her own medication. She becomes her own doctor at times. She decides how much she needs and injects herself with low doses of insulin. I tell her not to... but she doesn't care." (Jinadasa, 72y: Husband, MC, ZBI Score =36)

Some caregivers were also concerned about the level of dependency of the PwD. The majority of them reported that they wanted the PwD to live an independent life for as long as possible. However, it appeared with the advancement of illness, the PwD became overly dependent for personal care and demonstrated behavioural problems which were difficult to manage without assistance:

"I can't attend to any other domestic work. She needs me near her all the time. She screams when I'm not in her vicinity… Even for five minutes. It drives me mad. If I'm not there my husband has to stay with her…" (Kumari, 47y: Daughter-in-Law, MC)

Caregivers reported that attending to daily care needs without help was *'exhausting*':

"When he passes stools, I get fed up... It's really hard for me... There is no limit to washing the house. Sometimes he does it all over the house… Then I have to wash the entire house. The children won't come to help me out, so I have to do everything by myself... It's exhausting..." (Niluka, 38y: Daughter, MC)

Older caregivers also had one or more medical conditions, such as diabetes, hypertension, back pain or arthritis. One spouse, who was also a main caregiver, had chronic renal failure, and three of the main caregivers were diagnosed as having depression and were on medication. It appeared that the older caregivers experienced caregiving as a challenge with their ill-health. They also tended to neglect their own health, and forgot their medication or regular clinic attendance due to increased workload, stress and caregiving responsibilities:

"With this trouble I tend to forget my pills. Some days I don't attend my pressure clinic. I can't leave her alone at home. What to do? My children can't take leave on several days for attending our clinics." (Soma, 71y: Former Employer, MC, ZBI score =24)

"I wear a pacemaker. I was asked to attend chest clinics too... But I don't go there anymore as I can't leave her alone at home." (Sriya, 66y: Sister, MC, ZBI score =45)

However, some of them were concerned about their personal health as they felt that they needed to be *'fit and well'* in order to continue caregiving:

"I have bad kidneys. I have to stay fit and well in order to take care of her. I don't like to take medicine, but I swallow nearly 20 pills a day, because I need to take care of her." (Jinadasa, 72y: Husband, MC, ZBI score =36)

It appeared that the caregivers experienced fear, worry and uncertainty regarding the future consequences of caregiving, most commonly concerning potential injuries of the PwD (such as falls), inability to continue care with increasing age and the PwD becoming increasingly dependent over time:

"The biggest problem is figuring out how to feed her like this... What happens if I have to hospitalise her, who will be the bystander [an informal helper who is not a hospital employee]? I can't do that, can I? I can't even walk properly with my legs. […] I'm afraid to leave her alone... What if she breaks a leg or an arm while wandering on the road or gets hit by a vehicle? Who takes the responsibility for taking care of her? I hardly manage to get her things done at this age of mine." (Soma, 71y: Former Employer, MC, ZBI score =24)

The caregivers seemed to be concerned about their increased care needs and caregiving responsibilities in terms of vigilance, safety and the well-being of the PwD. For example, Chandrika expressed her sense of burden related to safety of her mother. However, according to her ZBI scores it was only a mild burden:

"I've spent many sleepless nights. I'm afraid to leave her alone when she wanders. What if she falls?" (Chandrika, 60y: Daughter, MC, ZBI score =6)

The older caregivers experienced a significant psychological burden of worrying over future care arrangements, quality and adequacy of the care provided, support needs and financial requirements for meeting these demands of caregiving:

"Even though I'm physically weak and old, still I can manage these without being a burden to my children. But if this gets worse. I don't know. I'm afraid, what if I die before him? […] The children have their own lives to carry on, I don't need to become a burden to them. What if I couldn't continue to do this much longer? [Pause] Facing future is… the future is… [long pause] I have no idea." (Nimala, 64y: Wife, MC, ZBI score =33)

Some concerns were about caregivers' own future:

"*I'm scared of my future... I feel sad and helpless. What will happen to me if something happened to my sister? [cry]" (Sriya, 66y: Sister, MC, ZBI score =45)*

The majority reported that their worries and fears over illness and care arrangements were high in the early stages of the caregiving process. However, findings presented in Chapter Seven, Section 7.4.1, showed that uncertainty over future circumstances and the perceived burden of care decline with increased awareness and exposure to the situation (e.g. Samanmali's Story, See pages 231).

Some caregivers tended to have negative attitudes towards gender-related aspects of care and providing care for a PwD of opposite gender was seen to represent an additional burden:

"He is my father... However, he's a male. I feel awkward when I have to clean and touch his private parts. My husband also doesn't like when I do that." (Niluka, 38y: Daughter, MC, ZBI score =32)

"Even though he's my husband I sometimes feel uncomfortable to clean him and wash his private parts. But since there's no one else to do that… I do it myself." (Nimala, 64y: Wife, MC, ZBI score =33)

However, gender appeared to have a lesser impact on the family members who accepted their caregiving role and when they focused on caregiving activities as caring for someone who is unwell rather than focusing on their kinship. Their ZBI scores indicated mild to moderate burden:

"If I am away from home it's my husband who looks after my mother. He does everything willingly and with love. He even assists her in going to the toilet and cleans her after." (Kumari, 47y: Daughter-in-law, MC, ZBI score =18)

"I don't feel any difference. When we were small, father might have done everything for us... I am not ashamed to do it myself... Now... I'm helping a sick person here, why would I hesitate to do it?" (Rani, 52y: Daughter, MC, ZBI score =29)

Three male main caregivers reported that they took the responsibility of caregiving only as there were no female siblings in their family (who in Sri Lanka would ordinarily be expected to take on this role), and other male siblings refused to care for the PwD. It appeared that some of main caregivers experienced a severe burden of care when it was not their choice but a perceived responsibility. For example, Nirosha experienced a severe burden in all the domains, which also reflected through her high ZBI scores:

"I am a prisoner in my own home as it is impossible to leave her for one minute… just one minute, you know... [Cry] This is not what I wanted, I wanted to have some free time for myself with my own family. I never could get rid from her [PwD] responsibility. Feels like I am losing my dreams" (ZBI score =88)

Some of the main caregivers explained that they felt they were *'captive'* because of the caregiving role:

"It's true I volunteered for this. But now I feel like I'm trapped. I am dying to go home... [I can't] go on a trip with my kids during their school vacation. Now last week my little one cried a lot when he went back to the hostel [where Suneetha's children are currently living]. What to do...? I volunteered to help but now it seems I have no escape... It feels like I am no longer enjoying taking care of her. I feel like giving up." (Suneetha, 50y: Relative, MC, ZBI score =32)

"A lot on my plate": Playing multiple roles other than full-time engagement in caregiving

Most of the main caregivers who took part in this study appeared to be multi-taskers and adopted multiple roles and responsibilities in addition to their caregiving activities. They were shouldering various responsibilities in the family as housewives, babysitters and second wage earners. It appeared that these caregivers experienced burden when they were failing or struggling to alter their usual household chores in order to adjust to their full-time caregiving role:

"I'm a housewife. I cook for my husband and family, look after my grandchildren and my mother. It's difficult for me to commit full-time to her... I can't leave the rest of my family behind; you see." (Kanthi, 62y: Daughter, SC, ZBI score =19)

"There are things that needs to be done, but how to? I have no time for my personal work. You know... I only have time for myself during night-time, one or two hours, maximum." (Samanmali, 55y: Daughter, MC, ZBI score =26)

Spending 24 hours a day with the PwD seemed like a considerable burden to the main caregivers, especially when they did not have any respite, or did not receive adequate support from the rest of the family; or in the cases where the PwD was aggressive or irritable towards them:

"Sometimes he opens the tap in the back yard and plays with the mud like a child. He behaves childishly. I'm exhausted trying to keep him clean and safe." (Nimala, 68y: Wife, MC, ZBI score =33)

"I am always exhausted. Spending a day with her is not easy. I follow her wherever she goes. I can't help falling asleep if I sit for a while." (Sriya, 66y: Sister, MC, ZBI score =45)

Dependency, wandering and irritable behaviours of the PwD often increased the risk of injury and the need for greater input from the caregivers (for example, vigilance and safety precautions) which increased their burden of care:

"I don't feel him as a burden so often. But, yes... There're situations... like when he repeatedly pulls out his catheter. There are bad days when he becomes so irritable... and troubles me too much... When this happens, I feel like 'What a burden!' And I get angry; even shout at him..." (Saman, 48y: Son, MC, ZBI score =14)

"No one can control him when he's agitated. […] When he runs away from home, everyone gets worried, and starts looking for him... It is such a burden. Whole day we have to keep eye on him." (Rani, 52y: Daughter, MC, ZBI score =29)

Both Saman and Rani expressed a significant emotional burden, even used the word 'burden' yet rated their burden as fairly low on the ZBI.

According to some caregivers the burden was related to work-life imbalance, stress, and lack of rest and sleep:

"*At times I think; what is this life of mine? There's no freedom; no sleep; no time for my kids. I am multi-tasking. Have to go to my job, attend look after the children plus care for my father... All the responsibilities lie on my shoulders...*" *(Saman, 48y: Son, MC)*

Caregiver burden had negative consequences on the quality of the care provided. For example, some caregivers reported that sometimes they paid less attention to the PwD and caregiving due to increased workload:

"I forget to give her pills sometimes... I have a thousand and one things to do." (Kumari, 47y: Daughter-in-Law, MC)

"Some days I have no time to shower him. The children say Grandfather stinks, but I let him be… Because… because, I'm too tired…" (Niluka, 38y: Daughter, MC)

During the interviews the caregivers were asked about their own health, including their psychological wellbeing. Some of the caregivers reported that they were diagnosed with depression and were taking medication by the time of interview (some even presented their prescriptions and medications):

"I can't sleep, I get angry so often and I feel so sad about myself. Last time when I went to the dementia clinic, the doctor asked me to take pills for depression." (Nirosha, 31y: Daughter, MC)

Most main caregivers reported their experiences using phrases such as *'feel exhausted', 'overwhelmed with work', 'fed up', 'stressed', 'depressed', 'unhappy',* and *'frustrated'* and highlighted their need to *'take a break'*:

"*It's like an endless battle from morning to next day morning. I am exhausted and feel helpless... I feel so lonely... Yes... There's no one to help me... All I need is one hour... just one hour away from her... away from home... everything... I am dying to go out just for an hour, have fresh air and to feel like myself again." (Nirosha, 31y: Daughter, MC, ZBI score =88)*

"I feel guilty": Emotional burden of long-term caregiving

Some of the findings described in the Chapter Seven revealed that the caregivers experienced emotional burden due to guilt, frustration, and a sense of failure despite their engagement and commitment in caregiving activities (e.g. Nelum's story, page 208). Their emotional burden appeared to exceed the physical burden experienced by caregiving activities.

A main caregiver reported a significant burden (ZBI score =55) and said he feels guilt for what he '*had said and done*' to his mother due to his anger and misunderstandings:

"I feel bad now. I treated her like a beast. Whatever it is, she is my mother... I really feel ashamed of myself. [Cries]" (A Son: MC)

Caregivers often reported feelings of anger and low mood in some circumstances, such as when dealing with a PwD's uncontrollable, repetitive or irritable behaviours. Shouting at them, threatening, giving up on care and sometimes punishments (e.g. hitting the PwD or using physical restraints) were also reported

as a result of caregiver burden (more examples were discussed in Chapter Seven, Section 7.3). However, such reactions to anger were always followed by guilt and frustration. These subsequently increased caregivers' sense of burden and often resulted in sense of failure and dissatisfaction with the care they provided:

"At times I had to shout at him... like when he tried to take his sarong off... and pulled out his catheter. Sometimes I hit his legs saying 'don't do this and that…' I cried later for my actions… It hurts my feelings when I happen to hit my father [tears]. But I often think, 'May it not be a sin!' [Cries]" (Saman, 48y: Son, MC)

"I know it's not right. But when I'm stressed and messed up, I yell at her... or I yell at my kid. She is just six years yet, sometimes I feel so bad... I am a bad daughter... a bad mother... I feel like I'm a horrible person [Cries]." (A Daughter: MC)

It appeared that family disputes and arguments over their emotional reactions arising as a result of caregiving caused more distress and burden to the main caregivers:

"My husband several times warned me not to hit the child. I shout at him too... It's just I'm overwhelmed with work... Perhaps I'm crazy... I have forgotten how to smile. I'm not happy anymore. Even though I try my best to be nice to them, I just fail every day. I am a horrible caregiver, aren't I?" (A Daughter: MC)

One family suffered with guilt when reflecting on their ill-treatment of the PwD even after their death. For example, the main caregiver said, he had to lock his brother in a room in order to control his aggressiveness and wandering. He was unable to attend to his brother's personal needs in the later stages of his illness as

he was working full-time elsewhere. He appeared to still feel ashamed and guilty, even a year on from the death of his brother:

"I'm ashamed to tell you this. [pause] I've yelled at him while providing care. When he died I think we all felt relieved... But when I think of our past I feel guilty... I feel like I couldn't do much. With my work and other responsibilities, I couldn't do my best for him. I loved him, but I was tired... anger was unavoidable [smile]." (A brother: MC, ZBI score =23)

Following her father's death Niluka said:

"Now they [family members] say 'we miss the good times with him'. But they didn't help me when I needed it most... They could have done it. Sometimes I feel guilty for not being able to look after him well. I couldn't give him the best. He died in the hospital like he had no one." (Niluka, 38y: Daughter, MC)

However, as discussed in Chapter Seven, the majority of the caregivers were able to find positives of their caregiving journey despite its relentless demands and challenges.

8.1.2 Broader sense of burden driven by the family and social context

Findings indicated that the caregivers also experienced a significant burden driven by the family and social context related to issues and challenges such as misunderstandings, family disputes, lack of support, and social influences such as stigma and shame towards dementia and caregiving.

"They don't believe father/ mother has an illness": Misinterpretation of forgetfulness and BPSD

Findings showed that most of the secondary caregivers and extended family members who had less contact with the PwD commonly denied or refused to accept dementia as a disease which requires treatment, or misinterpreted BPSD due to lack of awareness or their negative attitudes and illness perceptions. Some family members interpreted BPSD as *'purposeful acts', 'deliberately trying to create issues'* or *'behaving badly'* (See Chapter Six, Section 6.1 for examples). These perspectives and reactions among the rest of the family members and neighbours negatively affected on the main caregivers as they caused disputes, misunderstandings, lack of support for caregiving activities:

> *"My elder sister doesn't like when father visits her as he caused many family disputes. My nephew is still angry at me as I once fought against him to save my father from accusation. [...] My little sister took him to her place, but she too got fed up with him so quickly. My other sister's husband refused to keep him there. […] Others… they don't even visit us anymore... Even now father argues with my husband, says unnecessary things to him. When he [husband] gets angry he doesn't even care about [my father's] age. He has yelled at me several times 'You keep your father; I am leaving this house!' and several times he left the house." (Rani, 52y: Daughter, MC)*

Disagreements within the family could be stressful and affect decision making related to caregiving, which caused distress for the main caregivers. It appeared that family members had conflicting opinions regarding treatment options and

care arrangements, sharing caregiving responsibilities and financial matters. One family reflected on their experience as follows:

Suneetha: At the beginning he was reluctant to take her [the PwD] to see a doctor. No matter how much I tried to explain to him that she is not normal, he refused to believe it. Instead, he blamed me for saying so. (ZBI score =32)

Kelum: Yes, she really got on my nerves when she insisted we need to see a doctor. For me everything was normal... and I didn't want to accept it. Then she threatened me saying she will leave home as she couldn't bare it [Kelum's mother's behaviour] anymore. So, I had no choice, that's how we met a doctor at first... ha haa! [laugh] (ZBI score =51)

Kelum laughed when he said this, perhaps as a coping strategy to deal with difficult emotions - such as guilt - while reflecting on memories of his mother's condition.

Some caregivers reported that they faced difficulties with the neighbours because of their misunderstanding of the BPSD:

"I heard [a neighbour] has pushed my mother once for plucking flowers from her garden. She even threatened us once and tried calling the police... We tried our best to explain to them about mother's condition, but it was no use."

(Gayan, 50y: Son, MC, ZBI score =13)

The involvement of the extended family members, friends and neighbours in care-related decision making appeared to increase caregiver burden to a great extent. In order to *'avoid getting blamed'* some of the caregivers tried to please the family members and relatives by following their instructions for care and practicing the treatment methods suggested by them:

"I do not believe in them [Ayurveda treatments] too much. I did it because, otherwise they [extended family members] think I'm not interested in getting him cured."

(Nimala, 64y: Wife, MC)

Caregivers were at risk of ceasing to love and care about the PwD if there is a lack of understanding and misinterpretation of BPSD as *'deliberately behaving badly'*. It also negatively affected the quality of the care provided:

"He hit me with an umbrella at the clinic…That day I felt like leaving him on the road and letting him die there..." (A daughter: MC)

"We all thought he was trying to create family disputes and we gave up on him. […] Who knows it's an illness? If we knew about the awfulness of this condition [dementia] earlier, it could make our lives much easier... and father's too." (Rani, 52y: Daughter, MC)

Such incidents negatively affected the caregiving process and quality of life for both the PwD and caregivers. There was also a high risk of the PwD being abused and mistreated as a result of caregiver fatigue (Incidents of control, giving up on the PwD, ill-treatment and physical abuse were discussed in Chapter Seven, Section 7.3).

It appeared that the dysfunctional family interactions and family members' negative reactions towards caregiving represented a severe burden for the main caregivers:

"My husband yells at me when I attend his [PwD's] personal care... I ask him, 'What else I should do? He is my father. If I'm the one who is doing the cleaning and seeing things, there shouldn't be a problem for you...' [Sigh] Not only him, the children don't like it either... I'm sick of their troubles. Actually, father does not trouble me like they do." (Niluka, 38y: Daughter, MC, ZBI score =32)

In some cases, the main caregivers expressed a huge emotional burden as they could not cope and endure PwD's suffering. For example, Niluka said that she wished that her father would die soon as this would be a relief for all concerned:

"They [other family members] like it when he's not at home. So, I had to send him to the hospital… at this very end stage of his life. They don't want him back home. [Cries, …] I just can't see him suffer like an animal... Sometimes I feel like it's good if he died soon. I want to see an end to his suffering, and mine. I am suffering a lot looking at his condition [Cries]."

"I want his permission": Influence of patriarchy

The majority of family units in Sri Lanka are patriarchal and decisions are made by the father or adult males in the family (Vithanage, 2015). Most of the main caregivers who took part in the study were female and not heads of family. Some female caregivers reported that they had to obtain *'approval'* or *'permission'* from their spouses, sons or adult males in the family to keep the PwD in the house and most care-related decisions were made by them. These caregivers reported that continuing to provide care at home was a challenge and burdensome when other family members refused to live in the same household as the PwD. For example, Nelum's husband gave permission for her sister with dementia to stay at their home. This permission came with conditions and Nelum was asked to admit her to

the mental hospital once the husband found her sister's behaviour annoying to him. According to ZBI scores, Edwin (*ZBI score =35*) demonstrated a high level of burden when compared to Nelum (ZBI Score =8):

"When she [the PwD] was brought to this house I said, 'She can stay here until it doesn't affect my freedom. You can continue your duty or whatever, but it's up to you to make sure she doesn't interfere with my freedom.' I allowed her to stay here with sympathy you know... But this time she got on my nerves. I mean I had enough with her shouting and aggressiveness... So, I forced my wife to send her to the mental hospital, where she should be." (Edwin, 68y: Brother-in-law, SC)

Most female caregivers were not able to make decisions on behalf of the PwD. It appeared that having to '*obtain permission*' contributed significantly to experiencing caregiver burden. Not only that, the *'permission'* was often not granted or was taken away in the middle of the caregiving journey.

In some situations, the family support for caregiving was also reported as *'poor'* or *'less'.* Niluka said:

"I feel like I'm abandoned. Some days they don't even care to talk with me. They want my father to go away. They hate me for keeping him in the house. I want him to be with me till he dies. But, I'm helpless."

It appeared that the caregivers experienced severe emotional burdens as a result of patriarchy and the unhelpful attitudes of their spouses, children and other family members. For example, Nirosha was concerned for her mother's future care arrangements if her husband did not allow her mother to live with them. Nirosha's husband lived abroad when her mother developed dementia and she had been

hiding it from him. She said; *'It will soon become a problem'* as her husband will return home in couple of months:

"I wish I could be happy. But I'm terrified I haven't told him a thing about her illness yet... I can't even imagine what to do if he asked me to send her away. I'm sure he wouldn't tolerate her being with us in this condition. In fact, he never liked her." (ZBI score =88)

"They don't help me": Lack of support from the PwD, family members and others

Findings indicated a considerable heterogeneity in the type and level of support received by the main caregivers. During the caregiving process the caregivers appeared to expect support from the PwD, the family and relatives, as well the wider social circle. Their expectations included support with caregiving activities, appreciation of their commitment, emotional support to cope with the burden of care and also financial support. As explained in Chapter Seven, caregivers who received good support often experienced less caregiver burden irrespective of the severity of the PwD's dementia and the duration of caregiving. However, the findings also revealed that the lack of support caused distress and burden to caregivers.

Older adults in most extended families have shared responsibilities which help the family to function as a unit; for example; working, babysitting and doing daily household chores. Changes to these shared functions due to dementia was challenging to the main caregivers and it increased the sense of burden felt by both the caregiver and the entire family. For example, Nirosha experienced double caregiver burden when her mother was diagnosed with dementia as she lost the support her mother provided as the babysitter:

Nirosha: My brother sends me money, but I need him here… with me. I'm the only person available to look after my mother. My kid is still small, mother used to baby sit. Now I have to look after both of them, I feel sick to death.

Brother: I understand her concerns. But I'm helpless too. I wish I could stay, But I have to go back in few days' time. Or else we don't have money for any of these [living and mother's treatments].

Nirosha: Yes, I was bit relieved as he was here this month.

Due to caregiving role confusion among the family members, some showed resistance to support the main caregivers and refused to engage in caregiving activities. Hiding information from each other [during illness] also created issues which added to the caregiver burden:

"Neither of them [husband and daughters] take part in any caregiving activity. I feel helpless and abandoned... feel so depressed. […] my daughter always tells me to dump him to a care home. […] Sometimes I cry alone. (Niluka, 38y: Daughter, MC)

It seemed that over time caregiving became the sole responsibility of the main caregiver and the rest of the family members tended to reduce their involvement in caregiving activities. They also reported that family members have '*forgotten*' and *'neglected'* them and were less likely to understand main caregivers' workload and emotional needs:

"At the beginning it was a teamwork. But now they think it's only my responsibility. Let's say I got ready to go somewhere once in a blue moon... They yell at me like I neglect care. […] I'm tired, no sleep most of the nights. I can't go anywhere... not even to the temple…" (Sriya, 66y: Sister, MC)

One family had conflicts over property. The main caregiver reported that other family members once threatened to kill her if she did not transfer the PwD's property to them:

"She was abandoned by her daughters, badly beaten and starving when she came to me... They threatened me too. They even came to my house looking for her several times. Finally, I had to inform the police." (A daughter-in-law: MC)

"They don't appreciate me": Lack of appreciation

Sriya appeared to feel resentment that the family members do not appreciate her years of commitment to care. This is reflected in a comment by Sriya's brother-in-law, who responded by saying *'she doesn't do much'*:

"She sometimes says she wants to leave us. But we don't care… She has nowhere to go. She gets angry about it. In fact, she doesn't do much. She just cooks, spends the day with my wife [PwD]... does the feeding and bathing, that's all." (Sena, 72y: Husband, SC)

It appeared that lack of appreciation towards their care commitments often led to negative emotional reactions from main caregivers, such as anger and frustration. Some caregivers questioned their commitment and thought of ceasing caregiving as a result.

"There was a time I often questioned myself, 'do I need to go through this…?' Those days I was so angry at her and frustrated. I was depressed, even took pills. There was no appreciation for whatever I did for her." (Kumari, 47y: Daughter-in-law, MC)

The majority of main caregivers expected appreciation from the PwD and other family members for their commitment to care; therefore, lack of appreciation

seemed emotionally challenging for them. Some caregivers seemed to experience low mood or even depression.

"I am devoted to her. I don't even go home to see my children because I don't want to leave her. But the day she scolded me [in front of visitors] I felt there's no use in how much I do for this woman... She never appreciates my efforts… I felt like she was so ungrateful." (Suneetha, 50y: Relative, MC)

"Sometimes she blames me... Says I'm not her child. She hates me for taking care of her. I need more courage to tolerate her. To tell you truth, living with her is now becoming really difficult for me." (Samanmali, 55y: Daughter, MC)

"We were ashamed, got blamed and isolated by the society": Influence of society on caregiver burden

Accepted social norms for caregiving, and the cultural and traditional beliefs about care and treatment methods for mental illness were also considered as challenges by the majority of caregivers, and they experienced an indirect burden of care as a result. A widely accepted social norm in this context was that women (daughters or daughter-in-laws) had a greater level of responsibility for providing care (Vithanage, 2015). It appeared that daughters in the family were expected to adopt more caregiving responsibilities for parents than sons were:

"I am the daughter and it is my responsibility. She was with me all these years and I can't ask my brother to take her now." (Sujeewa, 55y: Daughter, MC)

Controlling the PwD's behaviour was considered the responsibility of the caregivers, and blame was directed towards the entire family when they failed to do this. Examples were given in which others in the community blamed the families

in situations where the PwD went missing for several days and was found wandering along roads by the police, or when they plucked flowers or stole things from neighbours. The psychological burden perceived by the caregivers increased due to the resulting shame and blame:

"She walks far to pluck flowers and forgets the way back home. One day a neighbour brought her home having found her plucking flowers from someone's garden. They blamed us you know... They think we don't keep eye on her. What shame!" (Nirosha, 31y: Daughter, MC, ZBI score =88)

"My father went missing two times. But the police officers did not pay much attention when I asked for their support to find him. Instead, they treated me as if it was my fault... I was so helpless." (Niluka, 38y: Daughter, MC)

There were also situations where the main caregivers and other family members were publicly shamed:

"Once he ran away from home and we couldn't find where he went. And somehow the police contacted my elder brother and blamed him. 'Is this the way you look after him...?' What shame...! No one realises how difficult for us to keep him in our homes, he runs away." (Rani, 52y: Daughter, MC)

"She screams inside the shop, accuses me in front of my customers saying I don't take care of her. Sometimes she begs for money from the strangers for her food and medicine. Oh, such shame! I can't face society because of her now, I feel so humiliated." (A Son: MC)

Caregivers often took precautions to avoid being blamed and embarrassed. It appeared that the caregivers' responded to such incidents by restricting their

activities, for example not leaving the house or visiting neighbours. As a result, the freedom and autonomy of the PwD was also restricted:

"If I go somewhere now... I lock the door outside so she can't come out..." (Nirosha, 31y: Daughter, MC)

Dinesh experienced a sense of burden as he had to face many challenges arising from the social context. He explained:

"My mother has told someone who walked in the road that I do not treat her well... That person has complained to the police... The police came to my place, arrested me and locked me up for one night... No one believed me. The police thought I mis-treated my mother. I couldn't prove my innocence... She goes here and there wearing ragged clothes all day… So, who is going to believe me?" (Dinesh, 50y: Son, MC, ZBI Score =55)

Social norms and values dictate that the children should look after their elderly parents, so institutionalisation or failure to care is considered as neglecting these duties. Caregivers stated that meeting the social expectations of '*how you treat parents*' and dealing with the social stigma were challenging, so they generally continued to provide home-based care despite the burden this caused them:

"We have to deal with her behaviour, our own lives and also the social expectations. Many people outside do not know about this condition and they just blame us when things go wrong. They judge us and label us as children who neglect their parents... Those who criticise us today left us when we most needed their support. I have enough experience." (Dinesh, 50y: Son, MC)

"To be honest I'm not in a position do this anymore. But we can't send him away, you know. I don't want my children getting the blame from people for putting him in a care home." (Nimala, 64y: Wife, MC)

The above extracts reveal that the sense of burden was increased as the family members were compelled to care for the PwD at home even though the PwD require advanced care. Selecting formal care or institutionalisation was also perceived as a personal failure by the family members, resulting in self-blame and guilt:

"If I give up on him now, I won't be able to die in peace... I can't dump him in an elderly home." (Nimala, 64y: Wife, MC)

"I feel I can't take care of him at home anymore... But, I am afraid to send him to hospital or to an elderly home. People will think I'm such a hypocrite. After going through all this, I don't need to label myself as a bad daughter…" (Niluka, 38y: Daughter, MC)

Most of the reported incidents revealed that the families were socially isolated as a result of stigma. This increased the caregivers' psychological burden and also impacted negatively on their daily lives. For example, Gayan's family was *'ditched'* or *'not invited'* to any social events in the village due to his mother's behaviour:

Gayan: My mother was an active member in that elderly society held at the temple. But with her forgetfulness the other members cut her off. She wasn't invited to pilgrims anymore... not even for the monthly meetings. She was worried about that. Now anyway she can't go... But, what they did was not right. *(Cont.)*

Lakmini: Mother was wandering, stealing and plucking flowers from others'. This has become a huge problem for us now. Neighbours blame us… We are now quite socially isolated. Her recent behaviour is such a disgrace to all of us.

Caregivers reported that health care professionals (HCP) also held negative attitudes towards dementia, and refused to care for the PwD when he/ she was hospitalised:

"When she was in the ward with a fractured leg, she was trying to wander... A nurse asked 'why did you bring her here? She is such a trouble...' Honestly, she was troubling too much, and perhaps she was a difficult patient. I felt so helpless."

(Sujeewa, 55y: Daughter, MC)

However, there were differences between caregivers' perspectives towards stigma and shame. For example, Dinesh seemed to blame his mother (PwD) for causing embarrassment to him and their family, whilst Lal and Gayan thought the PwD was not to blame:

"We haven't done any wrong to them... It's true she screams, and sometimes she yells [using filthy language] at them... But she is not in a sound mind and we can't help with it, can we? We are also trying to cope with this situation. They don't realise it's because of the illness. They used to be nice neighbours. It's sad we don't talk to each other anymore." (Lal, 65y: Son-in-law, SC, ZBI score =48)

"Our neighbours keep complaining that she steals things and plucks flowers from their gardens... It's not stealing really. She just collects whatever she sees. We tried explaining them but failed... Some of them don't even look eye to eye now... What to do?" (Gayan, 50y: Son, MC)

Dealing with the issues arising from stigma appeared to be a burden for caregivers. Some of the family members were ashamed of the PwD's BPSD and were trying to hide their condition from those outside of the immediate family. Caregivers highlighted that PwD's behaviour caused '*embarrassment*', '*disgrace*' or '*humiliation*' to the entire family and had a negative impact on their social interactions:

"My eldest daughter complains, 'Grandfather always embarrasses us'. She doesn't even like to invite her friends to our home because of my father. She frequently asks me to dump him in an elderly home." (Niluka, 38y: Daughter, MC)

"I was so embarrassed the day she ate from [a visitor's] plate. That behaviour was shameful. Because of her we don't invite many visitors now." (Lal, 68y: Son-in-law, SC)

It also appeared that stigma related to mental illness indirectly increased the caregiver burden, so they frequently took precautions to hide the situation from their social network:

"We came to this place recently and we hardly know our neighbours. I can't take the risk of them having a bad impression on us. They don't know father has dementia you know." (A Daughter: MC)

"I have to think of my daughter's future... Only close family members and a few friends know about this. We try to keep it to ourselves." (Rose, 64y: Wife, MC)

"*My kid acts weird, perhaps [behaviour they] learned from her grandmother… Her teacher told me she does certain things at school; she thinks the child needs to be in a special class. I am ashamed. I don't want other kids and their parents to know about my mother's illness and treat my child differently because of that." (Nirosha, 31y: Daughter, MC)*

However, some caregivers said that social stigma was not a challenge to them and responded positively towards it. It was evident that for some, fear of shame and stigma towards caregiving instead had a positive impact and actually improved the quality of care in certain families. The caregivers tried to '*do their best*' to show society that they cared for the PwD well, since it was the socially accepted norm. Some even took the lead in raising awareness among relatives and neighbours:

"I'm not ashamed of his behaviour… If I let him wander and die on a road, then only I should feel ashamed… Instead of hiding it, I educated neighbours who questioned about his behaviour. Now people see how I treat my father. No one blames me for that. Actually, they help me now." (Rani, 52y: Daughter, MC)

It appeared that some of the neighbours and relatives were being opportunistic and trying to get advantages from the PwD and family during their difficult situation. For example, Nirosha said it was *'impossible to leave'* her mother unattended because her neighbours steal belongings from her house when her mother is home alone:

"There's no point talking about our relatives and the neighbours. I can never expect any support from them. They are really giving me a hard time... They steal things when I'm not at home. As my mother is forgetful, they take things away and never return. horrible. HORRIBLE people…[Cries] I'm so tired and feel so depressed… it's just too much for me…"

Another caregiver said she wanted to hire a paid caregiver, but as she distrusted strangers, she was reluctant to do this:

"I feel I can't do this anymore with my back pain and all… I thought I could hire a male care assistant. But, these days you can't trust strangers, you know...that's why I'm reluctant." (Nimala, 64y: Wife, MC)

8.2 Service gaps within the current health care system

This theme highlights the challenges faced by caregivers due to gaps in services within the existing health care system. The service gaps identified by the caregivers included: poor coordination of dementia clinics, lack of community-based services and facilities, poor communication between HCP and caregivers; and lack of integration between the medical model and other care models (which were discussed in Chapter Seven, Section 7.2.2). Most of the family caregivers appeared to be dissatisfied with the health services and facilities available to them. Caregivers reported that the current dementia clinic was inefficient as *'it was conducted in the hospital'* and *'far away from home'*.

Caregivers who had continued to attend the clinics complained that the clinic environment was not *'dementia-friendly'* as they faced difficulties in transportation

from home to hospital, long waits in the clinic, and insufficient time for consultation due to high patient numbers. Caregivers were reluctant to attend the clinic with PwD as PwD's physical and psychological condition resulted in agitated behaviour, incontinence and physical weaknesses:

"It was a nightmare. The clinic was overcrowded, we had to wait hours and hours for our turn. Mother sometimes weed in front of the crowd or slept on those benches. […] She gets very agitated in the crowd… Sometimes people were quarrelling. I couldn't take her there on my own. So I quit taking her there." (Kumari, 47y: Daughter-in-law, MC)

Not having a dementia clinic near to home was a challenge for most of the caregivers, especially if they preferred taking the PwD for consultation. Consequently, some caregivers preferred attending private hospitals and clinics instead of obtaining free government services:

"I am thinking about going to a private clinic. There are many private channelling centres nearby... It's really difficult to come to the clinic and it wastes so much time." (Nimala, 64y: Wife, MC)

As reported by the caregivers, there was poor coordination between clinics and specialist consultations within the current system as there were no combined services provided by those clinics for PwD and their caregivers. Most of the PwD and caregivers were also diagnosed with diabetes, arthritis, or hypertension. They were on medication and needed regular clinic attendance for these conditions. It appeared that the caregivers struggled to attend several clinics in a month (in

addition to the dementia clinic) to obtain treatments and consultations for these health conditions as again, no combined clinics were provided:

"I have to attend three different clinics for her... for diabetes, arthritis and this one... They are not in one place either. Since I can't take her to each and every clinic in this condition, I have to find someone to stay with her when I attend the clinics... This is very difficult for us. Doctors give me pills without seeing her in person. They just go through her reports." (Kumari, 47y: Daughter-in-law, MC)

Visiting several clinics with or without the PwD *'just to update the prescription and obtain pills'* was considered time-consuming, troublesome and ineffective. When the PwD did not attend the clinic consultation and prescribing of medication were based on the details reported by the family members who attended the clinic on behalf of the PwD. The caregivers who attended the dementia clinic reported that the professionals did not spend adequate time with them to provide information and explain the condition *'in a way they could understand'*:

"Perhaps they [The doctors] think it's not important for us to know [about dementia]. Each time I asked, they said it's due to forgetfulness. But no one told me what to do when she gets agitated or refuses meals. We don't know what we should do for her. But when I go to the clinic they ask me whether she has this and that… So I say 'yes', and they write the pills for her." (Sena, 72y: Husband, SC)

Another service gap was the lack of professional support for caregivers who provided care at home. It appeared that the caregivers felt helpless when performing advanced care at home as they lacked appropriate skills and confidence. Even though there is growing sense of confidence and acceptance over

time, most of the main caregivers who provided care for a person with moderate to severe dementia said it was difficult for them to meet the care needs and demands of the PwD without the support of a trained caregiver:

"I don't know how to change a catheter. He pulls off the catheter several times a day. It frightens me when I don't know what to do. I wish I was a nurse [smile]. I usually call [a neighbour who is a nurse] to do that." (Saman, 48y: Son, MC)

Caregivers reported their concerns towards lack of community-based services, such as home visits by nurses and volunteers and access to nursing homes, especially during the severe and end stages of dementia:

"We need someone who visits us often. Who talks to us, just like you did… if they can see both the patient and the carer at home, it's wonderful. Like a volunteer who can spend time with him… so I can have a little break... I have heard this happens in developed countries. Uh... Maybe I'm expecting too much!" (Nimala, 68y: Wife, MC)

Despite the stigma related to institutionalisation, some of the caregivers faced challenges as the elderly care homes refused to provide residential care for the PwD due to their lack of mental capacity and dependency:

"We went to an elders' home five to six times and asked whether they can keep him there... They didn't accept him, not even with money. The hospital also refused him. There are no elderly homes to take care of people like this." (Niluka, 38y: Daughter, MC)

Some of the caregivers reported that they faced difficulties due to lack of dementia-friendly facilities in the community and institutions (for example, in banks or supermarkets):

"I couldn't do any transaction from her account as she couldn't go to the bank. With much difficulty, only now do I have access to it. If bank officers were aware of [dementia] my life could have been so much easier than that." (Kumari, 47y: Daughter-in-law, MC)

It appeared that caregivers did not receive much information about dementia or psychological support from the HCP during their consultation visits for their own mental health needs related to the burden of caregiving, with the exception of current treatments, diagnostic tests and medication prescriptions:

"Doctors did some tests… a scan… you know... They told us that father has 'nerve death' or something. But nobody taught us what this dementia is. I got to know about it years later... I think most people who visit the clinic haven't got any idea about this." (Saman, 48y: Son, MC)

"They are too busy to spend time talking to us... Every day I think, I want to talk with her [the doctor] about my feelings. But not a chance! I am in so much pain; I too need a doctor now." (Nirosha, 31y: Daughter, MC)

However, some caregivers had received psychological support from HCP during the clinic visits even though it seems ineffective due to the lack of time and privacy for one-to-one counselling:

"I talked to madam. She listens to my grievances… But the thing is I don't get much time because others are waiting… The clinic is crowded, and you can't talk about personal matters there..." (Sena, 72y: Husband, SC)

However, most of the main caregivers who took part in the study were not attending the clinic. Therefore, the dementia unawareness, caregiver burden and

stress among them remained unaddressed. For example, Sena (a secondary caregiver) attended the dementia clinic and did not take PwD and the main caregiver with him. However, Sena was not provided with much information from the clinic. He did not demonstrate a good knowledge and understanding about dementia during the interview and he strongly believed in supernatural causes. Therefore, he could not educate other family members. He said:

"Even though I attend the clinic monthly, I don't know much. They [HCP] haven't told me much about it. I will tell you [MC] if there's anything you need to know. [Towards me] She can't understand any of these... neither do I… So I can't teach her."

8.3 Caregivers' suggestions to address their concerns, issues and challenges

Findings indicated that most of the key challenges to caregiving were caused by a lack of understanding of dementia among caregivers, perceptions of the socio-cultural and religious influences, heterogeneity of support and gaps in the existing health care system. Participants were asked for suggestions to address these challenges and to improve dementia care services. They suggested the following which may improve the quality of home-based care and the quality of services provided by the health care system.

8.3.1 Empowering caregivers

The term 'empowering' here refers to raising awareness of dementia, increasing informal caregivers' resilience and making them better prepared and more confident in providing home-based care (Nomura *et al.*, 2009). Lack of dementia awareness appeared to be the biggest challenge perceived by the informal

caregivers as the overwhelming majority of them reported that lack of awareness '*made their life hard'*. Participants suggested raising awareness at various groups. These include: caregivers and family members who care for PwD, older adults prior to the onset of dementia, wider community including school children, non-health professionals (e.g. Policemen, bankers) and also the general public.

"I didn't know anything about dementia. So how [could I be expected to] treat her well? I was fed up, stressed with all the problems I had to face because of her. See... This is the biggest challenge. I mean, not knowing about it even after we have lived with it for over a year. I'm glad I learned about this illness from you at least today." (Dinesh, 50y: Son, MC)

"Many people do not know about this illness. That's why many older adults with dementia become homeless. Family members see them [BPSD] as stubbornness or deliberate actions. My family thought, 'if he can remember past incidents why can't he remember most recent events?' See how many times he became homeless just because we were unaware about this! I think it's really important to educate people regarding this." (Rani, 52y: Daughter, MC)

Some suggested increasing awareness of how to prevent and control dementia before people developed the illness:

"You can make people aware of dementia before they get old. Now we all know about diabetes and cholesterol. We take care of and control sugar. Can't this be controlled the same way?" (Gayan, 50y: Son, MC)

"You need to educate people before you get the illness... Before they fall into this level [being affected by dementia]." (Niluka, 38 y: Daughter, MC)

"You can go on TV and educate people… like in Nuga Sevana [a daily live programme that discusses health matters]. People watch these... at least they will learn the name dementia." (Jayanthi, 66y: Sister, MC)

Another caregiver suggested that by conducting dementia awareness programmes in schools will be more beneficial to raise awareness of dementia among children and adolescents:

"The students always act as messengers to carry information to their families. I am happy to arrange a programme at my school [where she works] if you can come and talk." (Rose, 64y: Wife, MC)

Some of the caregivers were willing to volunteer in further studies and future public awareness programmes to receive more information and to share their experience among others:

"Count me in! I'm with you if you would love to speak and aware the public. Today it happened to my father. May be tomorrow my neighbour... We need to be educated on these new diseases. Don't we? I know how I felt being loss. I would do anything to help others not to go through the same." (Saman, 48y: Son, MC)

Findings also revealed a notable gap in dementia awareness among the people in the study context. Many participants were thankful for giving them 'opportunity to take part in the study' as it helped them to improve their dementia awareness and to increase understanding among the family members:

"To be honest with you, I had no trust when you first called. But you were the only person who asked how I felt being her caregiver and talked without judgement. That's the only thing compelled me to see you today. Thank you for your time! This information is priceless. You have no idea how much relieved I am. Wish I met you earlier." (Dinesh, 50y: Son, MC)

"I gave her up as I didn't know anything about the condition... Thank you for giving all this information. It was very useful... Now I know this is an illness... What was the name again? Ah… DEMENTIA right? [He wrote it down]" (Gayan, 50y: Son, MC)

The majority of caregivers said they require more information about dementia, especially on the risk factors, the nature of the illness, treatments, services and facilities available for informal caregivers and PwD. They also suggested the need for more time spent with HCP to discuss caregiver concerns and to learn the skills needed for home-based care. The current methods by which the caregivers received information on dementia and caregiving were health education provided by the doctors, nurses and social workers in the dementia clinic, the information leaflets issued from the dementia clinic, TV shows and magazine or newspaper articles on dementia:

"The day I went to the hospital I saw a leaflet… I brought it home and gave it to my other sisters to read… Now I look for articles when I read papers or magazines. It's good to know these things." (Kanthi, 52y: Daughter, SC)

"Accidentally I saw someone talking about dementia on TV... I asked my daughter to watch that." (Nimala, 64y: Wife, MC)

None of the caregivers said that they used online resources to learn about the condition. Lack of internet usage among older adults and not being familiar with medical terminology or not speaking English were seen as significant barriers:

"When my mother got to know about it from the clinic, we searched the term 'dementia' on the internet once. Honestly, I couldn't understand most of the jargon [laugh]. She doesn't use the internet at all." (Chamara, 23y: Grand Son, SC)

"I use my phone just to call people. I don't know how to use the internet." (Jayanthi, 66y: Sister, MC)

The expected outcomes of raising awareness were to enhance the chances of early detection of BPSD, enable the caregivers predicting and coping with the progressive nature of dementia and caregiving, empower them by giving confidence to provide adequate support to the PwD, minimise the resistance among other family members to having the PwD in the household and to increase support received by the main caregiver. According to some caregivers raising awareness would be a *'smart approach to reduce stigma'* towards the illness and would increase people's support for their journey:

"We hid it from others because of stigma and unawareness. I think people must know these new kinds of illnesses. So they act normal towards people like my mother." (Nirosha, 31y: Daughter, MC)

The participants highlighted the importance of raising awareness among the public; particularly professionals who work in services that are regularly used by older people, such as banks, the police, government institutions and elderly care establishments. They appeared to feel this might enable them to interact more

appropriately with the PwD through increased empathy and support and by reducing the stigma associated with dementia:

"You need to educate the police and staff in elderly care authorities. I was locked up like a dog because none of the officers knew about this. They need that awareness to help us, don't they? I can give you a list of times I got into trouble because they had no idea about this illness." (Dinesh, 50y: Son, MC)

"The community elderly society said no to my mother and isolated her [because of some incidents that occurred due to her BPSD]. I think you need to educate the community about dementia as people like my mother need their support more than anything." (Lakmini, 48y: Daughter-in-law, SC)

"I think they [police] should be educated about such conditions... My father went missing two times. But the police officers did not pay much attention when I asked for their support to find my father. They need to be aware of this in order to help us." (Niluka, 38y: Daughter, MC)

In addition to receiving information on dementia, there was also a desire to learn caregiving skills to increase confidence in caregiving, alongside life skills to cope with the burden and distress experienced by caregivers. Caregivers also reported that they wish to receive professional support to obtain training on basic caregiving skills:

"I learnt by experience watching the nurses and our therapist. It took me ages to feel confident in what I do for him. I'm serious! Family caregivers need to learn how to empty a catheter bag, how to turn, how to feed, and even simple massage or physiotherapy techniques. Simply, anything that might help us in long term care at home." (Saman, 48y: Son, MC)

The majority of main caregivers did not appear to have the basic caregiving skills necessary to meet the needs and demands of the PwD at the time of interview. They had had limited opportunities to educate themselves about caregiving but had learnt basic skills by experience or through occasionally observing professionals when the PwD was hospitalised. Earlier examples in this chapter showed that some had also obtained support from friends, relatives or neighbours who were HCP.

It appeared that caregiving was a challenge to most of the family members as they did not know the nature or the degree of caring the PwD needed. In terms of the skills required, the caregivers suggested providing essential skills training for daily caregiving activities (for example, feeding the bedridden PwD, changing their catheter, providing physiotherapy and stimulating the PwD) and ways to manage the PwD's irritable and violent behaviours:

"She is deteriorating day by day. I am clueless about how to continue this when she is bedridden. I struggle every day when changing her pad and when giving her a bath. You know, I need to learn to nurse." (Lakmini, 48y: Daughter-in-law, SC)

From findings discussed earlier in this chapter, it is evident that the overwhelming majority of the participants had experienced some level of burden and challenges of care. This highlighted the need for caregivers to learn coping skills:

"I don't know what to do when he keeps trying to run away from home or deny food. I need to learn how to care for him. I also need to learn how to cope with my anger, fears and stress." (Niluka, 38y: Daughter, MC)

8.3.2 Improving dementia care services

Caregivers suggested ways of developing a systematic community-based care system and workforce for managing dementia in the home. Their suggestions included encouraging home visits by nurses, public health midwives or trained volunteers and obtaining community support. Caregivers suggested that home visits by a trained HCP would be more helpful for them when compared to the current practice of attending the dementia clinic on a monthly basis without the PwD:

"It's really good if they can visit us rather than we go to the clinic. I stopped going to the clinic because I can't take her there anymore." (Chandrika, 60y: Daughter, MC)

"We would feel confident if someone came here to teach us what to do and how to. They'd also get to see the patient in person." (Saman, 48y: Son, MC)

Caregivers also reported that they needed regular monitoring of care, guidance and emotional support from an HCP:

"She [the PwD] was very happy when she got to know that you are coming for a visit… She must have asked about it like a hundred times. and was so impatient to see you. She sometimes needs attention from someone outside the family I think." (Jinadasa, 72y: Husband, MC)

Caregivers also suggested improving community services for PwD and their caregivers. These suggestions included establishing dementia-friendly elderly care homes, day-care centres for PwD and volunteers to support in home-based care:

"I've heard in developed countries they have nursing homes for people like her. My Son lives in [a HIC], I remember he said; older people can go to day centres and do certain activities, or carers visit their homes. It is unfortunate that we don't have such services in this country. We need this kind of support to relieve our burden."

(Sujeewa, 55y: Daughter, MC)

Their final suggestion was providing integrated health services for both PwD and caregivers; for example, integrated clinic facilities:

"I wish we had just one clinic. So I can get everything done by one visit. I mean, a clinic for both of us…" (Kumari, 47y: Daughter-in-law, MC)

8.4 Chapter summary

This chapter presented the issues and challenges of informal dementia care through three themes: caregiver burden, gaps in service within the current health care system and caregivers' suggestions to address their concerns, issues and challenges. Findings indicated that caregivers experienced a significant burden related to caregiving activities and due to the influence of extended family and social context. The sense of burden experienced by the main caregivers was made even more difficult due to their age, gender, physical and psychological health. Caregivers' emotions, personal beliefs, values and attitudes towards caregiving also influenced their perceived burden and the challenges faced. Lack of awareness

and socio-cultural influences such as stigma and shame were also important determinants. Social support and support for caregiving activities from family and neighbours received by the main caregivers appeared to vary across the study sample.

In many cases, the caregiver burden explicitly indicated in ZBI scores was not fully reflective of the level of burden indicated in interviews. For example, burden reported in most of the quotations suggested severe burden, yet the caregivers gave fairly low scores in ZBI. Reasons for this contrast may be that the specific domains of burden (e.g. physical, emotional or social strains) cannot be illustrated by giving an overall score, and also quantitative measures may not capture many details as in the qualitative methods. Therefore, ZBI scores may not be a very useful measure of caregiver burden for this particular group.

Service gaps identified by the caregivers included: poor coordination of dementia clinics, lack of community-based services and facilities, lack of understanding and poor communication between HCP and caregivers and lack of integration between the medical model and other care models. Caregivers suggested that most of their challenges and gaps in services within the current system could be overcome by empowering caregivers and by improving dementia care services; for example, by educating them about dementia and caregiving, introducing combined clinics, initiating the services of nurses and volunteers for home visits, developing day care facilities in the community.

The next and final chapter presents the discussion of key findings, strengths and challenges, and the conclusion of the thesis.

Chapter 09

Discussion and Conclusion

This chapter discusses the key findings of the thesis within the context of existing dementia and caregiving literature, taking a comparative and critical standpoint highlighting the significance and relevance of the findings. This chapter also discusses and evaluates strengths and limitations, potential implications for policy and practice, and future research directions in light of the findings. The chapter concludes with a section on my reflections and recommendations.

9.1 Overview of the thesis

The phenomenon of interest of this thesis was to elucidate a deeper understanding of the views, perceptions and experiences of informal caregivers for people with dementia (PwD) in Sri Lanka. I decided to explore individual and shared beliefs, thoughts, attitudes, assumptions and experiences of the informal caregivers on conceptualising the meaning of dementia and caregiving for a person with dementia (PwD). Accordingly, after thorough literature review on dementia caregiving and a systematic review on dementia research activity in Sri Lanka, I developed the research question– 'What are the views, perceptions and experiences of informal caregivers of older adults with dementia in Sri Lanka?'. In order to address this research question, I developed three specific objectives. They are: (1) to describe the meaning of dementia and the meaning of caregiving, (2) to explore care practices and experiences of the informal caregivers, and (3) to explore the concerns, issues, challenges and caregiving needs among informal

caregivers. This was an exploratory inductive study informed by phenomenology as its methodological approach, in-depth semi-structured interviews as the method of data collection and Interpretative Phenomenological Analysis (IPA) as the method of data analysis. The findings emerging from the data analysis addressed the research question and the specific objectives of this thesis. The following is a discussion of my findings.

9.2 Summary of key findings

The essence of the phenomenon of informal caregiving for PwD was uncovered by the findings. This included the meanings attributed to dementia and caregiving role by the caregivers who took part in the study. Table 9.1 summarises the key findings of the thesis in relation to super-ordinate themes, themes and subthemes that emerged from the interviews.

Table 9.1: Overarching super-ordinate themes, themes and subthemes emerged from IPA

Super-ordinate Theme	Themes	Sub-themes
Meaning of dementia	Illness perceptions	"It is not an illness but a normal part of ageing" Illness Identification Denial
	Perceived causes of dementia	Stressors Cultural and religious factors reflected through beliefs - "Karma" or "God's wish" - "Fault of the stars" - "Revenge"
Meaning, Practice and purpose of caregiving	Connectedness	Togetherness Communication
	Engagement	Motives for caregiving - "I do it with love": altruism - "It's my turn to pay back": reciprocation - "I'm committed to care": commitment - "It's my duty": responsibility Care models used by the caregivers - Bio medical model - Ayurveda model - Other care models influenced by the religion and culture
	Control	-
	"Awakening"	Learning Spiritual Awakening
Caregiver concerns, issues and challenges	Caregiver burden	Burden related to actual caregiving Broader sense of burden driven by the social context
	Service gaps within the current health care system	-
	Caregivers' suggestions to address their concerns, issues and challenges	Empowering caregivers Improving dementia care services

9.3 Discussion of the findings

9.3.1 Demographic characteristics of the caregivers

The participants of this study consisted of a group of informal caregivers including main caregivers (i.e., those who were involved in most of the care or spent the most time with PwD) and other family members. The main caregivers were the adult children (12), spouses (3), siblings (4) of PwD and one non-related caregiver. The majority of the main caregivers were female (70%). The only study on dementia caregivers from Sri Lanka reports similar percentages of female caregivers (Abeywickrema, Weerasundera and Ranasinghe, 2015). Social norms in Sri Lanka impose a caregiving role on women (Vithanage, 2015) in line with what is seen in a broad range of research settings and cultures where the majority of dementia informal caregivers are female (Cho, Zarit and Chiriboga, 2009; Kassaye, 2012; Chiao, Wu and Hsiao, 2015; Hossain *et al.*, 2018) and many are spouses and children of PwD (Cho, Zarit and Chiriboga, 2009; Reamy *et al.*, 2013; Shim *et al.*, 2013; Afram *et al.*, 2014; Gibbons *et al.*, 2014; Borsje *et al.*, 2016; Meyer, Cullough and Berggren, 2016; Hossain *et al.*, 2018; Peacock *et al.*, 2018). However, a recent literature review on dementia family caregivers in HIC (Australia, Canada, Norway, Sweden, USA and UK) suggests that there is an increasing trend of men undertaking a caregiving role, especially among the spouse caregivers above the age 65 (Hennings and Froggatt, 2019).

Among the twenty main caregivers, nine were aged 60 years or above; within the group of main caregivers, the age ranged from 31 to 74, (mean age 57.25 years; SD = 11.75). Abeywickrema *et al.* (2015) reported that 11.7% of the caregivers (n=9) were over the age of 65 years (mean age 49 years, n =77).

A majority of the main caregivers (n=12, 60%) were either unemployed, ceased their employment, or retired by the time of data collection due to the need for full-time engagement in caregiving. Rest of the main caregivers were engaged in care while being employed. These findings are in line with the findings of broader research on caregivers (both in other South Asian countries and in HIC) who had accepted their identity as a 'caregiving career' (described in Chapter Two, Section 2.3, page 51) (Pattanayak *et al.*, 2010; Todorova *et al.*, 2016; Mace and Rabins, 2017; Hennings and Froggatt, 2019; Oh *et al.*, 2019).

The study revealed that 80% (n=16) of the PwD lived in the same household with the main caregiver. The extended family system is still quite prevalent in Sri Lankan society (Vithanage, 2015) as in most other Asian countries (Pattanayak *et al.*, 2010; Chen *et al.*, 2014). Traditionally, many elderly parents live in the same house with their children and grandchildren and the younger generations caring for the elderly is an accepted social norm.

Cultural sensitivity is an awareness of how culture shapes a person's values, beliefs, and worldviews, with not only an acknowledgment that personal differences exist but also with respect for these differences (Mahoney *et al.*, 2005). The study revealed that 90% (n=18) of the study participants were Buddhists and 10% (n=2) were Christians, with a Buddhist spouse. Therefore, the findings discussed in the following sections show a strong connection with Buddhist philosophy as the views and experiences described by most of the study participants were influenced by their religious beliefs.

9.3.2 Meaning of dementia

Chapter Six presented the super-ordinate theme of 'meaning of dementia' emerged through the two themes: illness perceptions and perceived causes of dementia. The theme of 'illness perceptions' described how informal caregivers identify, understand and conceptualise the nature of dementia and PwD's forgetfulness and BPSD, whilst the theme 'perceived causes of dementia' described the views of caregivers in relation to possible causes for developing symptoms of dementia.

The findings of the current study revealed that members in the same family conceptualised dementia, identified the causes of forgetfulness and BPSD and reacted to them differently. In what follows, I discuss the findings in accordance with the attribution theory (Wong and Weiner, 1981) and explanatory models of illness (Kleinman, 1981; Weinman *et al.*, 1996) as these theoretical concepts are relevant and facilitate understanding of different views of the study participants.

Meaning of dementia according to attribution theory

Attribution theory describes the process of how people make causal inferences about their own and others' behaviours and how they answer questions about *'why'* it occurs (Wong and Weiner, 1981). According to this theory, people assign attributions systematically, which influences their subsequent behaviour and attitudes by making judgements to explain them (Polk, 2005). Previous studies in different socio-cultural settings have explained how caregivers attribute the cause of early BPSD using attribution theory (Markus and Kitayama, 1991; Sensky, MacLeod and Rigby, 1996; Kessler *et al.*, 1999; Hinton *et al.*, 2005; Krull, 2005; Polk, 2005; Hamilton-West *et al.*, 2010; Ferri and Jacob, 2017). As aforementioned, the caregivers of the current study held a range of illness perceptions and tended to

judge the causes of PwD's behaviour in different ways. These can be categorised into three dimensions: dimension of normality (i.e., judgement of BPSD as normal part of ageing), dimension of causality (i.e., judgements about whether the behaviour is internal or external to the PwD) and dimension of responsibility (i.e., whether the PwD is responsible for his behaviour or not and whether the behaviour is controllable or uncontrollable by the PwD).

Dimension of Normality

One of the key findings of this study was that the majority of participants normalised the early signs and symptoms of dementia (e.g. forgetting names, disorientation to time and place, getting lost when coming home from a relative's house), with the attribution of symptoms to being a '*normal part of ageing*' or to the individual's personality. Similarly, in a systematic review of thirteen qualitative studies, Hossain *et al.* (2018) report that South Asian dementia family caregivers who living in Canada and the UK also normalised the symptoms of dementia as characteristics of the normal ageing process or the personality of the affected person. According to Hossain *et al.* (2018), caregivers from South Asian region lacked knowledge about early signs and symptoms of dementia before their relative was diagnosed and were unable to detect the early cognitive and personality changes untill an outsider drew attention to them. McCleary *et al.* (2012) report that some South Asian caregivers living in Canada continued to believe that the dementia symptoms were normal even after seeking medical advice and having medications prescribed for the PwD. In support of the findings, Ferri and Jacob (2017) found that symptoms of dementia are considered part of normal ageing in many LAMIC and are therefore not perceived as requiring medical

care. A group of Anglo- American caregivers also perceived that BPSD were due to normal ageing (Krull, 2005). A meta synthesis of qualitative studies from the USA reports that African- American, Latino and Chinese caregivers living in Massachusetts also had similar views about normalisation of cognitive symptoms; however, lack of knowledge about dementia was the major reason rather than culturally influenced beliefs (Mahoney *et al.*, 2005).

Dimension of Causality

Within the dimension of causality, the caregivers attributed internal causes (e.g. ageing, smoking, alcoholism, stressful lifestyle), and external causes such as chronic physical or psychological illnesses (e.g. hypertension, diabetes, epilepsy or depression), stressful life events (e.g. death of a loved one, loneliness, retirement), social (e.g. death of a close family member, isolation, retirement), super-natural causes (e.g. evil spell, evil eye, witchcraft, demonic possession, astrological influence) and spiritual or religious causes (e.g. Karma, Sins, God's wish). Most caregivers often referred to the condition as *'an abnormal or unusual behaviour', 'a nuisance', 'madness', 'an illness caused by other physical or psychological conditions'* or *'some kind of mental illness'.* Only three main caregivers who were HCP used the term 'dementia' to describe the condition and a few others who updated their knowledge over time could describe the condition by commenting on the underlying pathology*, 'an illness caused by the death of brain cells or death of neurons'*. The overwhelming majority of caregivers gave cultural, religious or super-natural explanations to the onset of dementia symptoms. Therefore, the current study strongly suggests that caregivers' knowledge, socio-cultural identity influenced their illness perceptions and the identification of causes of symptoms.

In line with these findings, a systematic review on South Asian dementia caregivers who living in Canada and the UK reports that caregivers identified a wide range of psychosocial, physical, and mental problems (including diabetes, excessive tension or depression, sadness, anxiety, fear, social withdrawal, isolation, and loneliness) as causes of dementia (Hossain *et al.*, 2018). Another group of South Asian caregivers living in Canada thought that dementia is a punishment resulting from 'something the PwD had done wrong' (McCleary *et al.*, 2012). In addition, two studies that describe perceptions towards mental illnesses from India (Schoonover *et al.*, 2014) and Sri Lanka (Sumathipala *et al.*, 2008) report that affected people and caregivers attributed the onset of illness to environmental or natural causes (e.g. weather, and ill-wind), although this was not seen in the current study. Evidence shows that socio-cultural and religious identities of the caregivers are clearly associated with conceptualising the meaning of dementia regardless of the context they live (Bunn *et al.*, 2012; Hossain *et al.*, 2018).

Dimension of Responsibility

Within the dimension of responsibility, some of the caregivers in the current study attributed the symptoms of dementia as '*deliberate acts*' of PwD, *'bad manners'*, '*acting' or 'lying'* and '*not an illness'.* Similarly, in a qualitative study, Polk (2005) reports group of family caregivers from the USA experienced difficulty in differentiating between BPSD and PwD's personality and attributed BPSD to the PwD being *'lazy'* and *'spiteful'*.

Attribution of responsibility exhibited an association with the way caregivers reacted towards BPSD and forgetfulness displayed by the PwD. The caregivers who attributed the symptoms of dementia to bad manners of the PwD or considered

them *'intentional'* tended to demonstrate hostility and anger, resulting in criticism or blaming the PwD. PwD's repititive questioning, wandering and aggressiveness were also considered controllable behaviour, and this assumption resulted in increased rejection of the PwD's behaviour, punishments and using power to control the undesirable behaviour. In contrast, attributions of uncontrollability such as incontinence, inability to communicate, physical weakness and dependence increased caregivers' acceptance, tolerance and patience with the PwD's behaviour. In Comparison, Polk (2005) reports that his study participants justified the *'lazy'* and *'spiteful'* behaviour of their loved ones as *'loss of control with ageing'* and accepted them instead of blaming the PwD. These findings highlight the differences between the attributions of caregivers' from HIC settings and those of the current study.

Within this thesis, the caregivers often explained their attributions of responsibility by religious and cultural elements and reacted to PwD's behaviour differently. For example, those who attributed onset of dementia symptoms to religious or spiritual causes such as '*Karma'*, *'bad stars'* or *'result of witch-craft*' tended to place the blame on the particular cause perceived to have contributed to dementia onset. Those who thought that the PwD developed dementia due to the caregivers' fault (e.g. the forgetfulness and BPSD were developed as the caregivers left PwD alone at home or gave them emotional stress; See page 184) tended to blame themselves or criticised other family members instead of being hostile to the PwD. In such situations they were more likely to show empathy, love and caring towards PwD. These findings align well with the postulations by Solomon (2001): 1. caregivers are less supportive and accommodating when conflict prompts

persistent negative moods and attributions, and 2. attributions are a part of larger mental schemas.

Meaning of dementia according to explanatory models of illness

The analysis revealed that the caregivers' explanations to dementia and its causation can be categorised into several explanatory models (described in Chapter 6, Section 6.2) Explanatory models consist of a person's views and perceptions about the nature of an illness, its cause, severity, prognosis, treatment preferences and other aspects of care (Kleinman, 1981). Leventhal, Nerenz and Steele (1984) proposed 'the self-regulation model' and described that an individual's illness representation is based around his/ her own ideas about severity, causes or consequences of their illness which, in turn, determine coping. Evidence suggests that caregivers' explanatory models of illness may differ between various ethnic and socio-cultural groups (McCabe and Priebe, 2004; Hinton *et al.*, 2005; Frostholm *et al.*, 2007; La Fontaine *et al.*, 2007; Petrie, Jago and Devcich, 2007; Hamilton-West *et al.*, 2010; Schoonover *et al.*, 2014).

Caregivers' explanations about the nature of dementia and its causes can be categorised into several explanatory models including bio-medical, Ayurveda, social, religious, super-natural or mixed models (i.e., combination of bio-medical model and one or more of other models). Most caregivers of this study held a mixed explanatory model when conceptualising the meaning of dementia. For example, some caregivers held a bio-medical model and believed that dementia symptoms (e.g., forgetfulness) were caused by pre-existing physical conditions or chronic illnesses (e.g., hypertension, diabetes, arthritis, epilepsy, head injury), and psychological conditions (e.g. anxiety or depression). Further, caregivers also

believed in religious (e.g. '*Karma*', 'God's wish') and supernatural influences (e.g. 'bad stars', 'astrological misalignment of the living house or planetary bodies', 'possession of supernatural spirits', or 'witchcrafts' such as evil eye, curses) which are directly linked with their perceptions of causation of the dementia symptoms. The findings of my study are very similar to the findings of another study from South India (Schoonover *et al.*, 2014) which has been carried out among a group of caregivers for people with chronic mental illnesses. According to this study, the caregivers conceptualised the causes of mental illness using a social model (e.g. mental illnesses are caused by factors such as financial or familial problems, death in the family, domestic violence, PwD's over-thinking, physical and mental weakness, habits such as alcohol, tobacco, or drug abuse) and spiritual or super-natural models (e.g. being cursed, given the evil eye, put under a spell or voodoo, astrological misalignments, bad stars or destiny). In contrast to my study, Schoonover *et al.* (2014) report that some caregivers identified the affected person as supernatural (e.g. godlike or a mermaid). In support of the findings for religious explanatory model, Sethabouppha and Kane (2005) report that a group of Thai Buddhist caregivers believed that bad *Karma*, acts of sin cause mental illness. Ethnic minority South Asian caregivers in the UK viewed dementia as *demons*' *or God's punishments* (Hossain *et al.*, 2018). (More evidence discussed in the dimension of causality section above). These findings affirm the existing evidence that the caregivers from non-westernised settings (e.g. ethnic minority dementia caregivers from Asian, African or African-Carribean origins) are more familiar with the explanatory models that are influenced by their identity, religion and culture, whereas caregivers from westernised settings are more familiar with bio-medical explanatory models (McCabe and Priebe, 2004; Hinton *et al.*, 2005; Sethabouppha

and Kane, 2005; Schoonover *et al.*, 2014; Hossain *et al.*, 2018). For example, two groups of African- American and Anglo- American caregivers reported causes of dementia onset as worry, emotional stress or a traumatic event (Wilkinson and Milne, 2003; Krull, 2005) while another group of caregivers considered dementia as a group of symptoms that occur when the brain cells stop functioning properly (Sayegh and Knight, 2013).

According to Frants Fannon (a philosopher and a psychiatrist whose writings were influenced by the existentialist and phenomenological perspectives), people develop meaning in daily life from their unique anti-colonial discourses (Yeh, 2013; Fanon, 2018). In his book 'Alianation and Freedom' Fanon argued that people create their own perceptions and knowledge from their geogrophical contexts (Fanon, 2018). He explains that people develop different identities (which he calls a 'postcolonial identity') based on culture, ethnicity, religion, social class or gender. Findings of the current study are in line with Fanon's ideas.

There are substantial variations of illness perceptions and identification of causes and BPSD within different ethnic groups; for example, a group of White British caregivers for people with Schizophrenia were more likely to name the condition as a mental illness or more specifically as Schizophrenia (McCabe and Priebe, 2004). They could cite specific biological causes, while non-White populations from Bangladeshi, West-African and African-Carribean origins named the condition differently and cited supernatural or social causes. An association between ethnicity and other caregiver characteristics, and the type of explanatory model preferred by caregivers was shown in another study using four ethnic groups which showed that most caregivers, including Anglo- European American

caregivers, held mixed explanatory models (Hinton *et al.*, 2005). The findings reported that majority of the current study participants also held mixed explanatory models.

Dementia literature across the globe reveal that caregivers' health literacy, level of education, knowledge and awareness on dementia, religious and socio-cultural beliefs, norms and values, myths, personal and family values and attitudes determine their ability to conceptualise the meanings of dementia and caregiving (Hinton *et al.*, 2005; Sethabouppha and Kane, 2005; Schoonover *et al.*, 2014; Shim *et al.*, 2013; Todorova *et al.*, 2016; Hossain *et al.*, 2018). However, the current study revealed that the conceptualisation of the meaning of dementia and caregiving was largely influenced by caregivers' socio-cultural and religious beliefs and personal values, thoughts, assumptions and attitudes, rather than their knowledge or awareness of dementia.

Association between meaning of dementia and ongoing care

Findings also indicate that religious and cultural beliefs play a role in terms of explaining the meaning of both dementia and caregiving. There was a strong association between caregivers' explanatory models of illness and the caregiving role. This also includes continuation of care and use of health care. This study revealed that caregivers widely used alternative care pathways (i.e. non-westernised, religious or traditional healing methods) which were influenced by their culture and religion even though they were aware about the westernised bio-medical model (See Chapter Seven, Section 7.2.2 for examples). Alternative treatment methods practiced by caregivers include: Ayurveda treatments (e.g. Hisakudichchi), religious and spiritual practices (e.g. Religious stanza (Pirith)

chanting, Pooja, Almsgiving), astrological remedies (e.g. horoscope reading) and traditional healing practices (e.g. Shanthikarma, devil dances, Bahirawa Pooja, spells and black magic; see Table 7.1, page 215). These alternative healing methods were practised as either first-line and sole treatment for dementia or as a complementary treatment along with western medical treatments. In contrast, findings from westernised contexts report caregivers who identify the symptoms specifically as BPSD (according to the bio-medical model) rather than as normal ageing or any other causes attributed to conditions such as stress or depression, would seek professional help for dementia if they perceived the symptoms (Petrie, Jago and Devcich, 2007; Hamilton-West *et al.*, 2010). Studies from westernised settings also show that native PwD and informal caregivers identify BPSD and diagnose dementia earlier than the ethnic minority groups living in those settings (Hossain *et al.*, 2018) and utilise more community care facilities when compared to migrated groups in the similar settings (Hinton *et al.*, 2005; McCleary *et al.*, 2012; Jutlla, 2013b).

The current study revealed that normalisation of symptoms, lack of dementia awareness, stigma and religious and socio-cultural beliefs were the persistent barriers in early identification of symptoms, delaying seeking medical advice and diagnosis of dementia. In line with these findings, a group of Chinese caregivers living in HIC were reluctant to seek medical care due to stigma associated with dementia in their culture, whilst a group of Latino- Americans show a strong cultural aversion to nursing home placement and institutional care of PwD due to perceptions of family obligations to care for older parents (Mahoney *et al.*, 2005). In contrast, studies show that native HIC caregivers are well aware of dementia,

more likely to identify dementia symptoms and seek medical treatment earlier than South Asian caregivers (Bunn *et al.*, 2012). In addition, a study from the USA reports that concerns about racism prevented some African-American caregivers seeking medical care despite their dementia awareness (Mahoney *et al.*, 2005). This evidence is in line with Fanon's views on colonialism, Black suffering, identity, freedom and liberation (Yeh, 2013; Sithole, 2015) in which he highlights that social oppression and rasism affect the health seeking behaviour of ethnic minority people live in HIC countries.

Most caregivers in the current study consistently admitted their lack of knowledge about dementia or reluctance to accept the symptoms. Except for seven main caregivers, other main caregivers were not familiar with the term dementia at the time of interview; many secondary caregivers and family members became aware of dementia during the interviews. I was the first person to introduce the term dementia to them. Findings also revealed that some caregivers first became aware of the symptoms when PwD were admitted to hospital for other reasons (e.g. falls, injury), or when pointed out by HCP, a friend or family members. Although the caregivers were living with the PwD for considerable number of years, some of the secondary caregivers remained in denial and still appeared not to have understood the nature of dementia, even if they had engaged with some form of dementia services such as the dementia clinic. Findings also highlight a significant gap in disseminating dementia related information and caregiving instructions to informal caregivers by the HCP (Will be discussed later). However, there is evidence that South Asian dementia caregivers who living in the UK and Canada also demonstrated significant unawareness and lack of knowledge about dementia

symptoms (McCleary *et al.*, 2012; Hossain *et al.*, 2018). In contrast, a study carried out among African American, Chinese, and Latino family caregivers reported that community physicians' failure to recognise dementia or refer to specialists was more problematic than the language or ethnic differences related to accessing care facilities (Mahoney *et al.*, 2005).

9.3.3 Meaning, purpose and experience of caregiving

Findings indicated that the informal caregivers perceived both positive and negative meanings of caregiving and had a range of experiences along their journey with the PwD. Caregivers role, caregiving patterns and responses to PwD's forgetfulness and BPSD were largely varied among the caregivers based on how they assigned meaning to caregiving. These variations of their perceptions and caregiving experiences can be explained to a certain extent by understanding how the caregivers derived meaning from their particular caregiving situations (Montgomery and Kosloski, 2009). Creswell (2013) stated that, the origin of 'meaning' is always social, arising in and out of interaction with a human community. According to Frankl (1959), caregivers make their experiences more meaningful by being able to grow as a result of facing difficult or stressful situations during the caregiving process.

The chosen IPA method helped me to understand how the caregivers discovered meaning and purpose of caregiving, and also their life, mainly through their lived experiences, involvement and engagement in long-term caregiving activities. Analysis revealed that attribution of meanings was unique and mainly influenced by each caregiver's explanatory models (i.e., illness perceptions and identification of causation which were discussed earlier in Chapter Six, Sections 6.1 and 6.2),

severity of dementia and duration of caregiving, personal and socio-cultural obligations that motivated the engagement in caregiving, history of relationship with the PwD and outcomes of caregiving. The following sections discuss the four themes presented in Chapter Seven: connectedness, engagement, control and 'awakening'.

Connectedness

The theme of 'connectedness' reflected a series of caregiver experiences which ranged from 'togetherness to distancing' and level of communication between the PwD, caregivers and their wider social circle (i.e., friends, neighbours, HCP and others who are directly or indirectly involved in long-term care). Findings indicated that many caregivers experienced positive aspects of connectedness in terms of *'connecting with each other', 'bonding', 'spending time together'*, *'supporting the PwD and caregivers'* and *'sharing memories'* (See pages 194-197 for examples). Caregivers of the current study considered their loved one's dementia as *'a blessing in disguise'* as it allowed the family members to *'become closer'* and *'team-up'* for caregiving. In the current study, PwD and the caregivers who spent much time together demonstrated stronger emotional bonding, empathy and understanding towards the BPSD as well as willingness to care, sense of joy, satisfaction and fulfilment (i.e., positive caregiving experiences) when compared to those who lacked the intimacy with the PwD. The study also revealed that the main caregivers who spent more time with the PwD had better communication, could understand the non-verbal clues, physical and psychological needs of the PwD better than others and 'become experts to hear what the PwD don't say' (e.g. Saman's Story, page 203). Similarly, a qualitative study from the USA also reports '*attunement*' that

helps the caregivers to communicate non-verbally and understand the PwD's nuanced and subtle shifts as well as changing care needs when the severity of dementia increased and verbal communication is compromised (Todorova *et al*., 2016). However, existing evidence also suggests that one can still find meaning in caregiving even without a previous positive relationship, without being blood-related or married to the PwD, especially if the purpose of caregiving is altruistic. For example, a group of paid informal caregivers caring for seriously mentally ill individuals have reported that they found meaning of their lives, self-fulfilment or self-actualisation (Rhoads and McFarland, 2000). In that study, caregivers tended to be motivated by altruistic purposes rather than considering 'caregiving as their duty or job'.

The current study also revealed that PwD wished togetherness with their family members and frequently expressed fear of *'being alone', 'sending away from home'* or '*dumping in an elderly care home'* (e.g. Mervin's Story, page 199). This is in line with a recent qualitative study from a HIC which reported that PwD prefer and are generally much happier to live in their own homes or familiar environments (Meyer, Cullough and Berggren, 2016). However, despite the PwD's willingness to be together, the current study also indicated that some caregivers intentionally distanced from the PwD due to increased distress and sense of burden (e.g. Sujeewa's Story, page 207), misinterpretations of BPSD, stigma or comparing them with pre-dementia incidents (See an example in page 179) and in some cases, due to lack of meaningful communication (e.g. Sarah's Story, page 208). A shift in relationships (i.e., togetherness to distancing), akin to role reversal (i.e., where the parent has become more like the child, or daughter has become more like the

'babysitter' or *'the nurse'*) was also revealed with advancing illness and the subsequent increase in care needs (e.g. Stories of Niluka and Samanmali, page 198). These findings are in line with evidence from westernised settings. For example, relationships change from 'togetherness to loneliness' as a result of changes in caregivers' daily lives and expectations; communication failure lead to distancing, as well as confusion, anxiety and worry among caregivers about being unable to understand the concerns of PwD (Meyer, Cullough and Berggren, 2016). Evidence from other studies shows unsatisfactory family relationships, prior incidents (such as conflicts with the PwD) and poor family functioning increase the caregiver burden when compared to individuals with satisfactory pre-dementia relationships (Steadman, Tremont and Davis, 2007; Tremont, 2011). Findings are also consistent with a descriptive phenomenological study from Sweden, which reports that the spouse caregivers experienced a distance and loneliness even they lived together due to lack of intellectual communication and due to the need for decision making without or on behalf of their partner (Shim *et al.*, 2013). This suggests that experience of different levels of connectedness along the caregiving journey is common across contexts and is not culturally influenced.

Engagement

Findings indicated that engagement in caregiving was very complex and nuanced; there was considerable heterogeneity in caregivers' motives, caregiving patterns as well as the care models used by family members. Caregivers of the current study were able to find meaning and purpose in being engaged in caregiving and to make sense of their identity as caregivers as well as human beings.

Motives for caregiving

The study revealed a range of motives (i.e., altruism, reciprocation, responsibility, commitment) that determined caregivers' enthusiasm to engage in care throughout their journey of caregiving. The majority of caregivers in the current study perceived caregiving as a positive experience and reported positive meanings derived from their caregiving. When reflecting upon the meaningful aspects of caregiving, many caregivers reported that it was love, a sense of belonging, sense of satisfaction, fulfilment, happiness, joy, togetherness what made their caregiving meaningful (e.g. Stories of Rani and Saman, pages 194, 210). Existing evidence from various cultural settings affirms these findings. For example, evidence reports that family caregivers experience enhanced meaningfulness of relationships through shared love, compassion and belongingness for the PwD (Shim *et al.*, 2011; Todorova *et al.*, 2016), a sense of purpose and pride in the caregiving role (e.g. considered the opportunity to care as a gift or privilege), providing care willingly and voluntarily (Shim *et al.*, 2013; Todorova *et al.*, 2016), by attributing the changes as a new challenge rather than as a burden over time (Shim *et al.*, 2013) and by acceptance of the caregiving role (Shim *et al.*, 2013). In an earlier study, Kramer (1997) reported that, when the caregiving became a positive experience, the caregivers increased their feelings of pride in their ability to meet challenges, improved their sense of self-worth, developed greater closeness in relationships, and provided an enhanced sense of meaning, warmth, and pleasure in the act of caregiving. Evidence from western settings suggests that this phenomenon is not only specific to the context or to dementia, but also has a broader relevance to any situation which involves long-term care (Etters, Goodall and Harrison, 2008; Lin, Macmillan and Brown, 2011;

Meyer, Cullough and Berggren, 2016; Burrell, Ives and Unwin, 2017). According to an existentialist perspective, people experience 'existential vacuum times' when one's goals are not met, when there are feelings of nothingness, meaninglessness, tension, anxiety, isolation and also hope (Farran, 1997). The existentialist perspectives also acknowledge that people find meaning in the midst of difficult life events, have potential to address the questions such as 'what does it mean to exist or to be human?' or 'why bad things happen to good people?' based on their lived experience, tension between 'being free to make choises' while assuming responsibility for 'what life sets before one', and the natural consequences of actions (Farran, 1997).

Findings also indicated different levels of care engagement (i.e., full-time commitment for caregiving to disengagement) among the family members. For example, some families who took part in this study engaged in caregiving as a '*team'* (e.g. Stories of Nuwan, Kumari and Sujeewa, page 195); some family members provided intermittent help such as spend sometime with the PwD so that the main caregiver can take a break (e.g. Stories of Jayanthi and Samanmali, page 196); some family members provided financial or psychological support to the main caregiver but did not engage in direct caregiving activities; some family members completely ignored both PwD and the main caregiver which also added additional stress and burden to the main caregiver (e.g. Stories of Sriya and Niluka, page 259). In line with the findings of current study, a study from India reports that in many extended families, total responsibility of care was on the main caregiver and there was less or no involvement from others; and therefore, no significant

difference in caregiver burden between the caregivers from nuclear families and extended families (Pattanayak *et al.*, 2010).

Findings of the current study revealed that some secondary caregivers (family members and relatives) tended to disconnect and disengage from caregiving activities mainly due to misunderstandings of BPSD, family disputes or sense of shame and stigma (See Chapter Eight, pages 258-268 for examples). Avoidance of caregiving due to caregiver distress and burden are commonly reported in the existing literature from both Westernised and Asian settings (Diwan, Hougham and Sachs, 2004; Liu *et al.*, 2012; Chen *et al.*, 2014; Wang *et al.*, 2014; Bieber *et al.*, 2017; Hossain *et al.*, 2018). These findings highlight the importance of support and contribution by other family members for main caregivers to continue their role with out negativity.

Findings also indicated a strong connection between the attribution of meaning of caregiving and their explanatory models of care. For example, some caregivers discovered meaning of caregiving in light of their moral and personal values (e.g. by showing unconditional love, empathy and compassion to the PwD, considering caregiving as a volunteer action, reciprocation, sacrifice or commitment), whilst others found the meaning of caregiving in the light of socio-cultural norms and religious teaching (e.g. being a role model to children, social obligation of looking after elderly parents, fear of stigma, Buddhist teachings). These findings are consistent with existing evidence and affirms the influence of caregivers' personal values, socio- cultural norms and religious beliefs on caregiving activities among Asian dementia caregivers (Wilkinson and Milne, 2003; Sethabouppha and Kane,

2005; Wong *et al.*, 2012; Chen *et al.*, 2014; Xiao, Habel and De Bellis, 2015; Ferri and Jacob, 2017; Hossain *et al.*, 2018).

Caregivers of the current study were motivated to care for PwD at home as it was implied by their social norms; society expected the daughters to take caregiving responsibility of their elderly parents (e.g. Story of Mallika, Kanthi and Neela, page 168). Similarly, in China and India women were expected to take on more caregiving responsibilities when compared to men (Pattanayak *et al.*, 2010; Wang *et al.*, 2014). It was stigmatised and considered disgraceful to let an elderly person live on their own or in a care home (See pages 262-268 for examples). Similar findings were reported in another study from Sri Lanka by Umayal *et al.* (2010). Therefore, despite the experienced burden and difficulties in functioning, most families continued care at home citing concerns for family ties and fear of social stigma pertaining to giving up on caregiving. However, the current study also revealed that some main caregivers experienced burden and challenges in *'providing care alone'*; as in most families, other family members were either away from home due to their work commitments; or some were avoiding the caregiving responsibilities. Including the findings of the current study, studies from LAMIC report that, recent socio-cultural and economic transitions in most LAMIC have caused dwindling of the extended family system and a shift in family values 'leaving older parents in an empty nest' due to migration, education opportunities or rise of dual-career families where both the spouses work, resulting in no one being available to look after older parents (Choo *et al.*, 2003; Patel and Shaji, 2010; Kim *et al.*, 2012; Chen *et al.*, 2014; Vaingankar *et al.*, 2016). Accordingly, this evidence highlights the negative influence of recent socio-demographic transitions on home-

based caregiving; as a result, most South Asian countries including Sri Lanka are vulnerable to losing a very valuable cultural principle of caring for the elderly.

A recent qualitative study from HIC reports that spouse caregivers found it difficult to cope without the support of family members or other informal care services (Meyer, Cullough and Berggren, 2016). Therefore, in HIC community support and nursing home placements are available in order to support PwD and their family caregivers (Dobbs *et al.*, 2008; Sloane *et al.*, 2008; World Health Organisation, 2015). It is also widely reported that institutionalisation of PwD towards the advanced stages of dementia increases the quality of care, and quality of lives of both PwD and their family members, and reduces caregiver burden to a large extent (Kwak *et al.*, 2011; Nikmat, Hawthorne and Al-Mashoor, 2011; De Vugt and Verhey, 2013; Bleijlevens *et al.*, 2015). However, findings of the current study and other studies from Asian contexts report severe stigma driven by the socio- cultural and religious context towards sending away elderly people from home and therefore, reluctance in placing PwD in nursing homes, despite the lack of family support, undue pressure and increased burden experienced by the informal caregivers (Pattanayak *et al.*, 2010; Sun *et al.*, 2013; Hossain *et al.*, 2018; Cao and Yang, 2020). In contrast to the views and perceptions of caregivers in Asia, in the westernised settings, institutionalised care for PwD is accepted and encouraged (Etters, Goodall and Harrison, 2008; Verbeek *et al.*, 2012; Chan *et al.*, 2013; De Vugt and Verhey, 2013; Phillipson, Jones and Magee, 2014; Singh *et al.*, 2014; Bleijlevens *et al.*, 2015; Stephan *et al.*, 2018).

Considering the religious influence on caregiving, the current study revealed that the caregivers were committed in caregiving as a meritorious act, a pay-off of sins

or shared suffering for a previous *Karma*, and following the Buddhist teaching of 'the Noble Eight-fold Path' to *Nirvana* (See Chapter Seven, Sections 7.2.2 and 7.4.2 for examples). The study also revealed spiritual or religious purpose of caregiving such as collecting merit for a better life in the next birth and living according to Buddhist teaching. According to Buddhist philosophy, providing care for the 'ill' is considered a meritorious act which helps to collect good *Karma* (Liyanaratne, 1996). Lord Buddha has explained the spiritual dimension of treating the 'ill'; in many *Jathaka* stories and has emphasised the importance of caregiving to the sick and elderly. He himself set examples of caregiving of sick by personally attending to care for an elderly monk called '*Puthigaththathissa*' who was abandoned by his fellow monks due to an end-stage putrid skin disease. Lord Buddha said, 'whosoever would wait upon me, he should wait upon the sick'. According to Buddhist philosophy, the motivation to care is '*meththa*', the altruistic love and compassion (Liyanaratne, 1996). Studies from Thailand showed that caregiving is a strong Buddhist belief in Thailand, and as a result, caregivers were able to maintain compassion throughout their caregiving process (Sethabouppha and Kane, 2005; Meecharoen *et al.*, 2013). A caregiver explanatory model influenced by Buddhism describes that the meaning of caregiving is living according to Buddhist beliefs; caregivers accepted their role and suffering and maintained compassion throughout their caregiving journey despite their suffering by practicing the 'Noble Eight Fold Path or the Middle Way' taught by Lord Buddha (Sethabouppha and Kane, 2005). In contrast, existing literature from westernised settings report that family caregivers found meaning by believing it as a choice of attitude, perceiving satisfaction in living according to their values in life, and having faith in a higher power or God (Peacock, 2011; Shim *et al.*, 2013; Todorova *et al.*, 2016). However,

despite the Buddhist teaching of accepting the illness and caring the affected individual compassionately, caregivers of the current study perceived shame and stigma. Social and cultural norms of family responsibility of caring for sick and elderly and related stigma towards neglecting this responsibility shaped caregivers' attitudes towards continuing care and accepting the caregiving career.

Accordingly, findings of this thesis highlight that caregivers' thinking patterns, cognitive schemata as well as socio-cultural and religious backgrounds are important determinants of engagement in caregiving, care practices and continuing home-based care for longer periods.

Care models used by the caregivers

The source of inspiration for views on meanings of overwhelming majority of the caregivers was derived from Buddhist philosophy (two caregivers were inspired by Christianity) and the socio-cultural norms integrated in the context (discussed above). However, each caregiver's situation and circumstances made their experiences unique and different and therefore, each attributed different meaning to their caregiving experience. Findings indicated that the members in same family held different beliefs and attitudes towards forgetfulness and BPSD; contrary to each-others' views, beliefs and attitudes, there were disagreements between family members regarding the effectiveness of bio-medical model and other care pathways used by them (e.g. Kelum's Story, page 254). Findings indicated the purposes of practising alternative care models influenced by the religion and cultural beliefs as passing merits to the dead relatives, chasing away bad spirits, requesting protection and gathering sympathy from supernatural powers (See Table 7.1, page 215). A study in Gujarat, India reports that many caregivers sought

advice and treatment from healers or witch doctors for their mental illnesses and considered these traditional healers as *'Godlike'* or people with supernatural powers (Schoonover *et al.*, 2014). Findings also revealed that the caregivers used alternative healing methods as a mechanism of coping as these practices provided caregivers a sense of relief (e.g. Samanmali's Story, page 222).

Surprisingly, the current study revealed that the caregivers' explanatory models tended to change along their journey. As presented in Chapter Seven, Section 7.2.2, findings showed a trend of caregivers' initial thoughts, beliefs and attitudes shifting along their caregiving journey. Except for one or two caregivers, the majority appeared to accept the nature of illness and the caregiving career, and accordingly changed or updated their cognitive schemata over time with increased awareness, care engagement and experience of the outcomes of their caregiving styles. For example, Saman once strongly believed in super-natural healing, but completely gave up on them with his understanding of the nature of dementia (See examples in page 236). However, evidence suggests that it is very unlikely that people change their explanatory models since they are core beliefs or stable cognitive patterns which developed over time through life experiences from their childhood (Padesky, 1994; Sumathipala *et al.*, 2008). Therefore, this trend in shifting of caregivers' cognitive schemata can be a learning process through experience as explained under the theme of 'awakening' (See Chapter Seven, Section 7.4) or hope of cure and losing trust on the current care pathway as described below.

The caregivers tended to change their 'maladaptive' illness perceptions (such as part of normal ageing, not an illness, deliberate act of PwD) and identified the condition as an illness that requires treatments as they were acquiring knowledge.

Some experienced practical difficulties and ineffectiveness of current explanatory model held by them and they appeared to align to another model or used mixed models. For example, the main caregiver Sena (See page 219), continued to attend the dementia clinic while practicing traditional and religious healing methods to cure his wife with dementia.

The focus of caregiving, treatments and care needs also varied accordingly with the changes in their explanatory models. For example, in one hand, caregivers who initially believed in supernatural causes and followed traditional healing methods as treatments tended to take medicine when they learned about signs and symptoms of dementia (e.g. Gayan's Story). On the other hand, those who did not prefer western medicine and strongly believed in supernatural causes (e.g. Samanmali's Story), and those who had lost the trust in the westernised bio-medical model as there was no improvement tended to try alternative models such as super-natural or spiritual models including Ayurveda treatments, and religious or traditional healing methods (e.g. Stories of Samanmali and Sena). Those who did not trust on supernatural or religious causes of dementia tended to use only bio-medical model or none (E.g. Stories of Edwin and Rani). In line with these findings, McCabe and Priebe, (2004) report that perceptions towards the cause of illness are significantly related to treatment satisfaction, therapeutic relationships and acceptance of mental illness. Most participants of Schoonover's study in Gujarat, India believed in traditional healing for mental illness, rather than the bio-medical model; some preferred continuing treatments from both doctors and traditional healers (Schoonover *et al.*, 2014). Several authors report that ethnic minority groups living in HIC hold similar beliefs and attitudes, and thus deviate from the

medical care and support services available for PwD and family caregivers (Hossain *et al.*, 2018; Stephan *et al.*, 2018; Bieber *et al.*, 2019). These findings highlight that ethnic, religious and cultural identities of caregivers have a strong association with their selection of care pathways. All these evidence, along with the findings of current study, highlight the ineffectiveness of practice of westernised bio-medical model in the context, and therefore, the importance of blending caregivers' religious and socio-culturally specific concerns into existing health care practices in order to enhance home-based dementia management. In fact, this may not solely be associated with dementia caregiving; it could be argued that South Asians have similar concerns towards other conditions as well. Existing literature reports that religious and traditional healing has a long history in Sri Lanka and that it is still widely practiced, especially for mental illnesses including dementia (Liyanaratne, 1996; Simpson, 2007). The findings of the current study reaffirm the existing evidence related to religious and cultural practices in illness management in the context.

However, caregivers' preference for choosing a care pathway (i.e. westernised medical care or other treatments or healing methods influenced by culture and religion) was influenced by many other factors in addition to caregivers' explanatory models. These include: issues and challenges such as lack of dementia awareness (e.g. experiences of Sena, Sriya, Gayan, Dinesh and Samanmali), physical inabilities of the caregivers (e.g. Jinadasa's experience) heterogeneity of support (family support, financial or other; e.g. experience of Rani, Niluka and Nirosha), sense of burden (e.g. Experience of Nirosha and Niluka), stigma (e.g. Experience of

Nimala, Rose and Dinesh), and availability of resources (i.e., transport facilities, availability of herbs, etc.).

In summary, findings of this thesis highlight that caregivers' thinking patterns, cognitive schemata as well as socio-cultural and religious backgrounds are important determinants of engagement in caregiving and continuing home-based care. Findings of this study will also add novel insights to dementia caregiving literature regarding wide use of religious and culturally accepted healing practices in the home-based management of dementia as there is a significant gap in dementia research activity in Sri Lanka.

Control

In contrast to what I discussed above, regarding the positive aspects of caregiving, the caregivers who often experienced negative aspects of caregiving (e.g. lack of freedom or burden) perceived caregiving as a duty or responsibility. Some caregivers considered caregiving as control of PwD and conceptualised caregiving as 'babysitting' or similar to 'raising a child' in terms of attending ADL, their efforts of *'correcting'* PwD's behaviour and *'answering repetitive questions'*. Some caregivers restricted autonomy and freedom of the PwD concerning their safety and wellbeing (e.g. locking up the PwD to prevent wandering, forceful feeding, not allowing to do household chores). However, findings highlighted that the caregivers did not have a clear understanding of the progressive nature of dementia and increasing dependency over time, as well as that the PwD do not improve as would a child (i.e., new learning or correcting their behaviour). Mace and Rabins (2017) report that PwD should be given some freedom without affecting their safety; affection, reassurance and communication are the best ways

of dealing with the behavioural challenges rather than controlling, which the majority of caregivers of current study failed to do. A few caregivers in the current study reported that they give some freedom to PwD and include them in household chores, however it was not practical with many caregivers due to increased workload, need for vigilance, safety concerns and associated burden. Accordingly, the thesis highlights the importance of increasing caregivers' understanding and awareness of dementia symptoms, the progressive nature of dementia and their role, as well as extending support to main caregivers by sharing the caregiving responsibilities, in order to experience caregiving as a meaningful and pleasant activity. Existing literature affirms this idea and reports that such interventions make caregiving a meaningful and worthwhile activity (Haley *et al.*, 2008; Montgomery and Kosloski, 2009; Todorova *et al.*, 2016).

Awakening

The current study revealed that the caregivers dealt better with the inevitable changes once they accepted the nature of dementia and their caregiving role (See examples in Chapter Seven, Section 7.4). Caregivers chose to make the caregiving experience meaningful and also found true purpose and meaning of life through engaging in caregiving (i.e., being committed, accepting their role as a caregiver), and mainly by their personal growth (i.e., learning caregiving skills, coping skills, be kind to and loving the PwD despite the challenges and sense of burden), and by making permanent changes to caregivers' thinking patterns through these experiences (which they referred to as 'transformation of self'). The theme of awakening (i.e., the process of growth and empowerment of caregivers through increased dementia awareness, understanding and identity and acceptance of their

caregiving role) described how the caregivers derived strength from their challenges and empowered through past experiences and learning of caregiving and coping skills. The subtheme of 'spiritual awakening' reflected the descriptions of positive transformation of caregivers' lives along with their spiritual and religious understanding of the impermanence of life as well as the inevitability of change and suffering. Without consciously thinking about it, the interviews made the participants realise that their lives were now very different to how they had planned and imagined before their loved one developed dementia (e.g. experience of Kanthi and Samanmali, page 235). Studies from westernised settings report consistent findings on transformation of caregivers' lives in a non-religious approach. For examples, a longitudinal study on caregiver experiences using grounded theory reports that caregiving is a learning process that changed main caregivers' life over time (Lin, Macmillan and Brown, 2011); the outcome of change was regarded as positive when the caregivers received the required support. Another study reports, caregivers considered on 'living for day' rather than worrying about inevitable future and 'making the best of things' were seen as conscious decisions to make caregiving a positive experience (Hellstrom, Nolan and Lundh, 2007). Todorova *et al.* (2016) report that caregivers find fulfilling connections and interactions with the PwD when they 'make sense' of caregiving and caregivers' identity. Shim *et al.* (2013) report that a group of spouse caregivers in USA were able to find the meaning of caregiving through acceptance, peace and regular changes to their focus of everyday life. In line with the findings of the current study, a phenomenological study by Butcher, Holkup and Buckwalter (2001) reported the experience of family caregivers for those with Alzheimer's disease as: *'being immersed in caregiving; enduring stress and frustration; suffering*

through the losses; integrating dementia into our lives and preserving integrity; gathering support; moving with continuous change, and finding meaning and joy'.

9.3.4 Caregivers' concerns, issues and challenges

The findings for caregivers' concerns, issues and challenges were presented in three themes in Chapter Eight: caregiver burden, service gaps within the health care system and caregivers' suggestions to address their concerns, issues and challenges. Family caregivers' perceptions and attitudes towards the care engagement showed a significant impact on their well-being as well as on that of the PwD.

Caregiver Burden

Although many caregivers reported positive experiences of caregiving, distress and burden was also evident from recollections of caregivers about their own journey and via comparison of caregivers at different stages of care. Findings indicated that both male and female main caregivers experience burden at unique and different levels for different reasons. For example, women who cared for male PwD found it difficult because their BPSD were threatening, older female caregivers complained of their physical weaknesses and difficulty in physical handling of the PwD while daughters and daughters-in-law complained of having to multi-task as they have competing care roles (such as cooking, babysitting, household chores) other than the caregiving responsibilities. Men mostly experienced burden due to their other work commitments as they continued caregiving while working. Lack of time for one's own self due to full-time engagement in care and lack of support or respite care increased burden among both male and female caregivers. However, evidence

from westernised settings report higher burden among female caregivers. A qualitative study conducted among spouse caregivers for dementia reports female caregivers experience more burden than male spouses, they also demonstrated more physical and mental health problems, depressive symptoms and less participation in health-promoting activities (Gibbons *et al.*, 2014). A quantitative study on caregiver distress (Hirst, 2005) also reports higher burden among women when compared to men, and increasing distress over a longer period of caregiving (more than 20 hours per day up to five years) for both genders. However, according to existing literature women do more of the caregiving and therefore higher burden may reported among them (Prince *et al.,* 2004; Ducharme *et al.*, 2011; Gibbons *et al.*, 2014; Mace and Rabins, 2017). Caregivers in the current study were providing care for PwD in various stages of dementia for a period ranging from two months to over 5 years. Average life expectancy in dementia is reported between 5 to 9.3 years (Villapando, 2015); however, this has also been noted to range between one to 15 years depending on the cause and severity of dementia (Hoefer, 2009).

According to Zarit Burden Interview (ZBI) scores 50% (n=10) of main caregivers experienced mild to moderate burden, 25% experienced moderate to severe burden and 5% experienced severe burden. The only previous study on caregiver burden from Sri Lanka reports comparatively similar findings: 43% mild to moderate burden (43%), 26% moderate to severe burden and 6.5% severe burden (Abeywickrema, Weerasundera and Ranasinghe, 2015). However, the in-depth interviews revealed that the burden is much higher than the reported ZBI scores in many cases, and the caregiver burden explicitly indicated in ZBI scores was not

fully reflective of the burden indicated in interviews (also see Chapter Eight, Section 8.1). I argue that the ZBI scores were not a very useful measure of caregiver burden when used in this different cultural context (Sri Lanka) and the 'validity' of overall measures were questionable as it did not capture all the aspects of caregiver experiences. The discrepancy between the burden expressed during interviews and the ZBI scores indicates that the quantitative measures cannot capture a sensitive topic such as burden and qualitative methods can give more construct to this context. This finding therefore contributes new insights to previous literature.

Medical research has confirmed that stressed caregivers experience poor quality of life (Serrano-Aguilar, Lopez-Bastida and Yanes-Lopez, 2006) and are at increased risk of other illnesses, cancer and premature death (Pattanayak *et al.*, 2010). Increased duration of caregiving, increased severity of illness (Gaugler, 2014), constant stress and strain of the caregiving process adversely affects caregivers' health, especially that of elderly spouses (Pattanayak *et al.*, 2010; Villapando, 2015). The current study found most main caregivers themselves had medical conditions such as diabetes, hypertension, arthritis, back pain and some were also on medication for depression. Their physical and psychological health had an impact on the ability and confidence in continuing care. Gibbons *et al.* (2014) report similar findings from a westernised setting.

Caregiver burden in this thesis was discussed under two subthemes: burden related to caregiving activities with the PwD and the broader sense of burden driven by the social context (examples were presented in Chapter Eight, Section 8.1). Concerning the burden related to caregiving activities, most challenging

concerns experienced by the caregivers of this study were PwD's behavioural issues (e.g. wandering, aggressiveness and risk of falls), functional limitations (e.g. being bed ridden, communication failure, dependency in ADL). Existing dementia caregiving literature also show similar findings. Burden increase due to PwD's behavioural problems, safety issues related to falls and functional limitations (Chatterjee, 2008; Gibbons *et al.*, 2014; Villapando, 2015), which are also cited as the reasons for seeking nursing home or assisted living facilities (Caserta *et al.*, 1987; Sun *et al.*, 2013; Siddiqui and Khalid, 2019). However, the current study revealed that the caregivers continue home-based care despite their sense of burden mainly due to high moral values (sense of belongingness and love), socio-cultural influence (stigma) and in some cases due to lack of resources (e.g. no facilities for institutionalised care).

Caregivers of the current study experienced the sense of burden as inability to care, exhaustion or increased workload, and also emotional burden in terms of helplessness, loneliness, isolation, social alienation, fear, anger, frustration and guilt. Existing broader dementia caregiving literature across LAMIC and HIC also show similar findings (Etters, Goodall and Harrison, 2008; Pattanayak *et al.*, 2010; Kim *et al.*, 2012; Srivastava *et al.*, 2016). Findings from this study as well as existing literature across the world show that characteristics of the informal caregiver (e.g. age, female gender, physical illnesses, caregiving onset, duration of caregiving, *etc.*) and characteristics of the PwD (e.g. level of cognitive decline, physical dependency in ADLs, severity of BPSD and increased care demands) increased the caregiver burden to a great extent (Bruce and Paterson, 2000; Choo *et al.*, 2003; Etters, Goodall and Harrison, 2008; Pattanayak *et al.*, 2010; Nikzad-terhune, 2011; Beinart

et al., 2012; Abeywickrema, Weerasundera and Ranasinghe, 2015; Xiao, Habel and De Bellis, 2015; Vaingankar *et al.*, 2016; Sutcliffe *et al.*, 2017). These characteristics are also consistent with findings regarding caregivers for people with other mental illness (Siddiqui and Khalid, 2019). However, as the current study showed very clearly the overall care burden is a unique experience of individual caregivers.

Findings indicated that the caregivers also experienced a severe burden driven by the wider socio-cultural context. For example, caregivers of the current study experienced burden when they did not receive the 'expected support', are 'not appreciated' for their commitment and due to increased pressure from family and other causes such as financial matters, family disputes related to sharing responsibilities and engagement in caregiving activities (e.g. Experiences of Sriya, Suneetha and Niluka, Pages 260-261). Some main caregivers reported over-engagement of family members in care (e.g. unnecessary involvement of relatives in care related decision making and insisting that the main caregivers follow alternative healing methods) caused them to experience a higher caregiver burden compared to the burden they experienced due to activities with the PwD (e.g. experiences of Sena and Nirosha). As discussed previously (See page 303), the current study also revealed a lack of support to some main caregivers as a result of disengagement and avoidance of other family members. This also increased caregiver distress and burden, sometimes resulted in potentially negative reactions towards the PwD (e.g. neglecting care or abuse). Hoefer (2009) states that choosing one member to be the full-time caregiver and not supporting him/ her can have devastating effects on the particular caregiver, and also on the PwD due to the tremendous burden of caregiving. The current study revealed that

availability of transport, affordability of having a paid caregiver or support from rest of the family members in caregiving reduced caregiver burden. These findings are consistent with other studies - the demand for caregiving and burden is compromised with the level of support received from within and outside the family (Wang, Xiao, G. He, *et al.*, 2014), financial status of the family and support received by the main caregiver (Lin, Macmillan and Brown, 2012; World Health Organisation, 2015; Zwaanswijk *et al.*, 2013; Xiao *et al.*, 2014; Villapando, 2015). Therefore, supporting main caregivers is an important aspect of reducing caregiver burden and improving quality of care (Villapando, 2015).

Another aspect of caregiver burden was the attempt to conceal dementia symptoms from other extended family members or neighbours due to stigma, fear of rejection and social isolation (e.g. experiences of Nirosha and Rose, page 267). In line with these findings, another study reported that family caregivers experience stigma in communities where dementia was associated with insanity and mental illness rather than understood as a degenerative neurological disease (Xiao, Habel and De Bellis, 2015). Stigma is a recurrent theme in dementia literature; many studies on Asian caregivers report on stigma related to dementia (La Fontaine *et al.*, 2007; Sayegh and Knight, 2013; Ferri and Jacob, 2017; Hossain *et al.*, 2018) and stigma among South Asians seems greater when compared to other caregivers living in HIC settings (Nielsen and Waldemar, 2016; Bieber *et al.*, 2017; Choudry and Farooq, 2017; Hossain *et al.*, 2018; Stephan *et al.*, 2018). However, in contrast to these findings, McCleary *et al.* (2012) report that none of their participants (a group of South Asians living in Canada) spoke about concealing dementia symptoms from relatives or friends. The findings of the

current study and evidence from Asian populations highlight that burden driven by the socio-cultural context (for example, socio-cultural identities, religious beliefs, lack of dementia awareness and stigma) contribute greatly to perceived caregiver burden regardless of their geographical location or the country they live in (Bunn *et al.*, 2012; Sayegh and Knight, 2013; Chen *et al.*, 2014; Xiao, Habel and De Bellis, 2015; Nielsen and Waldemar, 2016; Choudry and Farooq, 2017; Ferri and Jacob, 2017; Hossain *et al.*, 2018). Overall, the findings of the current study show that caregiving experiences in the Sri Lankan context are generally quite closely aligned to those in other Asian countries. Findings also suggests a significant need for culturally relevant, community and family-based interventions, that are focused on providing support to main caregivers and other members in family, raising public awareness, reducing stigma and changing negative attitudes towards seeking formal support and institutional care. This may ease the pressure and burden on main caregivers and therefore, may result in improved quality of lives of PwD and caregivers, as well as in the quality of care provided.

Findings from HIC show that the period after the diagnosis was the most difficult part of the entire journey (due to physical and emotional burden related to care and living with the PwD) (Sanders *et al.,* 2008). In contrast, caregivers of the current study experienced more distress before the diagnosis (due to disputes, stigma and difficulties caused by lack of awareness) and towards the late stage of dementia (due to lack of support and the lack of skills to perform advanced care at home, dealing with wandering and making emotionally difficult decisions such as using physical restraints, admitting the PwD to the mental hospital when PwD's dependency and irritability increased). The contrasts between HIC and LAMIC

settings suggest a greater understanding of dementia in HIC in relation to the severity and the incurable, degenerative nature of dementia; the diagnosis would therefore be more difficult to deal with than for those who have less understanding and be hopeful of a cure, as in the case of current study. Caregivers of the current study faced difficulties looking for alternative healing methods for a cure throughout their journey due to their lack of awareness. These findings highlight the need for increasing dementia awareness in the study context and at the same time it is necessary to strengthen the family caregivers in terms of support and skills during this post-diagnosis period in order to enhance the quality of home-based care in Sri Lanka.

In accordance with evidence from other contexts, this study also revealed that the progressive nature of dementia and the complexity of care for a PwD increases the caregiver burden over time. For example, many caregivers reported that they have promised their loved one that they would look after them until death. However, it appeared that most caregivers had no idea of the extent of the difficulty of providing such care for the PwD when making that promise. Hoefer (2009) states that end-stage long term care facilities are a must for dementia and the caregivers should not feel guilty if they had to place the PwD in care homes when they are unable to continue care at home. However, the caregivers of current study experienced severe guilt and frustration for not being able to meet the caregiving expectations. Those who were caring for end-stage PwD revealed more emotional burden alongside the loss of functional abilities and deterioration of the PwD as it was difficult for the family members 'to let go of memories' (e.g. Sarah's Story, page 208) and 'see the suffering' (e.g. Niluka's Story, page 256). This sense of burden left

the caregivers feeling overwhelmed with issues of grief, guilt, self-blame and frustration. Caregivers also reported feeling relieved when the PwD finally dies. Similarly, other studies also report that persistent caregiver burden increased the risk of stress, despair, guilt, frustration, grief and less satisfaction towards the end of life care and it increased depressive symptoms among caregivers (Chatterjee, 2008; Etters, Goodall and Harrison, 2008; Xiao *et al.*, 2014). Several qualitative studies report that caregivers experience grief even before death of the PwD, speaking of being lonely, loss of companionship, freedom, and control (Chan et al., 2013; Meyer, Cullough and Berggren, 2016). Caregivers' anticipation and ambiguity about the future, anger, frustration and guilt were reported in these studies as core features of grief (Chan et al., 2013). These findings are in accordance with most existing caregiving literature which also suggests these findings hold across all the contexts of dementia caregiving (Hirst, 2005; Vikström *et al.*, 2005; Etters, Goodall and Harrison, 2008; Brodaty and Donkin, 2009; Schoenmakers, Buntinx and DeLepeleire, 2010; Nikzad-terhune, 2011; Steadman, Tremont and Davis, 2007; Tremont, 2011; Zarit, 2011; Lopez-Hartmann *et al.*, 2012; Ornstein, 2012; Ask *et al.*, 2014; Chiao, Wu and Hsiao, 2015; Griffin *et al.*, 2015; Villapando, 2015).

An unexpected finding with a cultural significance that emerged in this thesis was the experience of burden associated with PwD's gender. Some female caregivers reported a higher burden when they cared for a male PwD mostly due to the uncomfortable feeling when attending to personal care, and sometimes due to the difficulty in controlling their violent behaviours (see examples in page 228. Sometimes, other family members pressurised the main caregiver not to attend to

the personal care of an opposite gender PwD. Pattanayak *et al.* (2010) report similar findings from India, but the reason was the disruption to the decision-making system of the family unit when the eldest male in the family developed dementia. A study from Sweden reports that attending to the personal hygiene of the opposite gender PwD was perceived as the most stressful aspect of caregiving by the spouse caregivers (Meyer, Cullough and Berggren, 2016).

Challenges caused by information gap and gaps in existing health care system

Findings indicated that most of the concerns, challenges and issues experienced by the caregivers were due to their lack of understanding and awareness of dementia and BPSD (presented in Chapter Six, Section 6.1.1; Chapter Seven, Section 7.2.2 and Chapter Eight, Section 8.2). For example, lack of dementia awareness caused delays in seeking medical advice, poor compliance with treatments, abandonment of the PwD, lack of support and attention to caregiving due to disputes, misunderstanding and developing unhealthy relationships (disconnection) with the PwD and family members, negligence of care and increased risk of abuse, and, caregiver distress or burden. Similar evidence in the literature indicates that, particularly in LAMIC, many cases of dementia go undetected because of the lack of awareness (Prince, Livingston and Katona, 2007; Prince *et al.*, 2009). From a study in India, Pattanayak *et al.* (2010) report severity of dementia as mild dementia in 56.25%, moderate in 28.12% and severe in 15.63% of PwD in their sample, but none of the caregivers had sought help from a psychiatrist or joined caregiver support groups at any time despite the burden experienced. Caregiver burden in this study was measured by 'Burden Assessment Schedule' which is a culturally relevant measure developed by an ethnographic exploration in India. These findings are also consistent with South

Asian dementia caregivers living in HIC. Due to lack of awareness, caregivers tended to underestimate the significance of BPSD (Roberts and Clare, 2013; Hossain *et al.*, 2018) and caregivers denied PwD's access to post-diagnostic care, treatment and support as dementia is considered a normal part of ageing (Hossain *et al.*, 2018). Xiao and his team (2015) reported that a group of Vietnamese family caregivers living in Australia also denied symptoms of dementia, delayed seeking medical advice, getting a diagnosis and, treatment and refused dementia services, thus, experiencing a high level of caregiver burden due to their lack of awareness. Information gap and lack of dementia awareness among ethnic minority caregivers was a barrier to access available services (Jutlla and Moreland, 2009; Bieber *et al.*, 2017; Hossain *et al.*, 2018; Stephan *et al.*, 2018). Prince *et al.* (2016) state that low levels of dementia awareness among HCP and lack of training in detecting BPSD contribute to low rates of diagnosis (Prince, Comas-Herrera, *et al.*, 2016). However, the current study did not explore the views and experiences of formal caregivers, which needs to be explored in the future. A systematic review of qualitative studies on psychosocial factors that shape caregiver experience on diagnosis and treatment reports persistent barriers to early diagnosis of dementia as stigma, the normalisation of symptoms, and a lack of awareness about the signs and symptoms of dementia (Bunn *et al.*, 2012).

Even though the majority of caregivers claimed lack of awareness on dementia, all participants had experiences of how the health care system works in general. Except for one PwD, all others were clinically diagnosed with dementia and had been to the dementia clinic. Therefore, they were able to identify the gaps in the dementia services available for them and PwD by experience. Most caregivers

complained that the dementia clinics are over-crowded (See examples in pages 268-269) and that there is poor communication between caregivers and HCP (e.g. lack of information and poor psychological support; See examples in page 272). This study revealed that the health information provided by HCP is often inadequate and ineffective in reducing caregiver concerns. For example, crowded clinics lacked the privacy to ask personal questions and busy HCP did not have sufficient time for clarifications, providing detailed information or individual counselling during the consultation appointment. Sometimes the information received was inadequate and unclear, reducing comprehension. For example, Sena did not understand the health information received from the clinic, and therefore, he could not educate other members in his family (See example in page 269). These findings are consistent with a literature review by Petrie, Jago and Devcich (2007) that indicated inadequate and vague information, lack of reassurance messaging in medical testing and consultation impacted negatively on PwD and caregivers, caused more harm by increasing caregiver burden. As a result, some caregivers of the current study showed poor adherence to the medical model, lost the trust on prescribed medication and treatments and deviated from it. Reluctance to use available services due to lack of awareness, stigma related to ethnic identities was reported among South Asian caregivers living in HIC due to their lack of understanding about dementia (Jutlla and Moreland, 2009; Hossain *et al.*, 2018).

Caregivers of the current study also reported poor coordination of dementia services. Participants of the current study complained of difficulties as they did not have any dementia related community services or a formal support system for home-based care (e.g. Nimala's Story, See page 271 for examples). These

participants attended many out-patient clinics for treatment and for consultation on other medical conditions. There were no combined clinics available for consultation and medical care in one place. These clinics were *'conducted on different days'* and *'hospital was far away from home'*. Transport and difficulty in visiting these clinics with the PwD were a challenge for most caregivers; some even neglected their personal health as it was difficult to leave PwD at home. In contrast, evidence from HIC indicates the availability of programmes and services for caregivers including well planned community services, support systems, home visits by HCP and even voluntary services for caregiving (Davis *et al.*, 2009; Kinnaird, 2010; Monaghan, 2013). Evidence from the study context reports that community-based and home-based services for older adults are limited and available general health care is largely restricted to tertiary care hospitals (Marçal-Grilo, 2014; Fernando, Suveendran and De Silva, 2017; Senanayake *et al.*, 2017). Based on the Mental Health Policy in Sri Lanka 2005 – 2017, the National Institute for Mental Health (NIMH) trained community psychiatric nurses and allocated them to provide service across the country. The role of these nurses included extending mental health care beyond the hospital to the community, with active follow-up of patients to encourage treatment compliance, provision of domiciliary mental health care service, home visits, supervision of medication adherence, administering prescribed medication including depot injections and providing mental health education to people with mental illnesses, their family members and also the community (Fernando, Suveendran and De Silva, 2017). However, the current study revealed that this policy is not being fully implemented in the study setting. None of the participants reported about home visits or involvement in home-based care by any of the HCP to the date of interviews.

Findings also revealed the deficiency in person-centred care alongside lack of understanding and communication between HCP, PwD, their main caregivers, and other family members about caregivers' emotional or psychological needs. Studies from other LAMIC settings also report similar findings (Pattanayak *et al.*, 2010; Hanlon *et al.*, 2015; Ferri and Jacob, 2017). Studies also report lack of structured training (for both formal and informal caregivers)on the early identification and management of dementia (Shaji *et al.*, 2003; Pattanayak *et al.*, 2010), lack of community-based services and facilities for family caregivers (Patel and Prince, 2001; Cho, Zarit and Chiriboga, 2009). In comparison to the situation in LAMIC including Sri Lanka and many other Asian countries, evidence from most of the developed world reports well-established dementia care services in the community and primary care settings including professional and institutional support for the family caregivers to provide a quality care for their loved ones who developed dementia from the very early stages of disease (Burgio *et al.*, 2009; Nikmat, Hawthorne and Al-Mashoor, 2011; ADI, 2015b; Berg-Weger and Stewart, 2017; Hossain *et al.*, 2018).

Findings also revealed that health care system only focused on westernised medical care and there was no integration between the medical care model and other care models when planning and coordinating long-term care. However, the study participants held many socio- culturally influenced explanatory models of illness and there was no integrated approach seen in the existing health care system. In support, McCormack (2001) states the mutual recognition of caregivers' beliefs and values, and negotiation between HCP helps in providing better care. On this basis, a reciprocal relationship develops in which 'both parties grow as a result'

(McCormack, 2001). To develop a good relationship between caregivers and HCP it is essential that HCP listen, understand, value the voices of caregivers and build therapeutic-relationships in order to support caregivers (Clark, 2002; Jansen *et al.*, 2009; Miyamoto, Tachimori and Ito, 2010; Peeters *et al.*, 2010; Schoenmakers, Buntinx and DeLepeleire, 2010; Lopez-Hartmann *et al.*, 2012). Unfortunately, current study revealed there is no effective therapeutic-relationship between formal and informal caregivers at the dementia clinic.

Another challenge revealed was the lack of professional support in providing advanced care towards the end-stage. Caregivers frequently reported difficulties in feeding, attending to personal care (e.g. toileting and cleaning) without assistance due to lack of confidence and skills. They also reported incidents where the elderly homes refused to admit the PwD due to their lack of mental capacity and dependency (e.g. Niluka's Story, Page 271). Similar to these findings, other studies from South Asia also report residential care homes refusing to admit PwD (Patel and Prince, 2001; Chang *et al.*, 2009).

Another important finding of this study is that the living environment of caregivers' (including neighbourhood and wider-community) had a significant impact on caregiver burden. Caregivers frequently reported difficulties faced by due to discouraging behaviour of neighbours (e.g. experiences of Nirosha and Gayan - disputes, stealing things when the PwD is alone at home, family treated differently by their communities due to stigma; also see page 268 for examples), lack of dementia-friendly facilities in the community and public institutions such as the police, banks or supermarkets (e.g. experiences of Dinesh and Niluka, pages 274, 278), lack of support and judgement from police officers when the PwD went

missing (e.g. experiences of Niluka and Rani, pages 278). In contrast, findings from HIC settings report availability of services and support for caregivers such as programs that help locate missing PwD (Villapando, 2015), and policies concerning dementia-friendly communities (Ward *et al.*, 2017). On the other hand, the widely practiced bio-medical model largely ignored such concerns of caregivers. Therefore, findings suggest the importance of raising public awareness and establishing integrated dementia services in the study context.

Support needs and suggestions to improve

Support needs suggested by study participants include empowering caregivers (by raising their dementia awareness and increasing confidence through education and improving caregiving and coping skills) as well as improving dementia care services in the context. Informal caregivers requested opportunities to increase dementia awareness (e.g. educate them during clinic visits, awareness programmes in the community, use mass media to inform people). As discussed in the above section, raising dementia awareness at various levels seems to be an effective way to manage dementia in the study setting as it may help to reduce stigma, change negative attitudes and beliefs towards dementia and motivate caregivers to seek medical advice and to take part in caregiving. Findings highlight the importance of basic caregiving skills, coping skills and communication skills for main caregivers and family members to solve their day-to-day caregiving challenges (presented in Chapter Eight, Section 8.3.1). Some PwD may not reach the end-stages before passing; therefore, caregivers may experience either a rapid or a very long caregiving process. The current study revealed that over time, caregiving gets harder; therefore, early preparation of caregivers can be useful for

them to be prepared for what is coming. In support of these findings, several studies show that early detection of dementia and support seeking can be improved by increasing dementia awareness (Shaji *et al.*, 2002; Ramos-cerqueira *et al.*, 2005; Li Huang *et al.*, 2013) and health and wellbeing of both PwD and the caregivers can be improved through raising awareness and empowerment (Strech *et al.*, 2013; Walker, 2015; Troche, Willis and Whiteside, 2019). Face-to-face teaching or using mass-media (TV and newspapers) would be the best methods to raise awareness among this group of caregivers as most of them were not familiar with on-line information and internet usage.

Caregivers also expected better understanding of their concerns and a closer relationship with the HCP along their journey of caregiving. Their suggestions included home visits by HCP rather than PwD visit the clinic. Their argument was the HCP could understand the situation better if they visit PwD and could provide more personalised support to PwD and caregivers (e.g. educate family members, supervise the caregiving activities and take more time to listen to their concerns). In support of these suggestions, a study from HIC show that nurses can support family caregivers to cope with the role disruption, caregiver burden and improve interaction with the PwD through counselling and skills training (Garity, 2006). Concepts of family nursing also highlights that a trusting relationship and recognition between formal and informal carers can be built through successful interaction between them (Carpentier and Grenier, 2012), and that it requires improved professional understanding of the complex social relationships and functioning of families (Carpentier *et al.,* 2008). Mace and Rabins (2017, p27 - 30) suggest that caregivers should be encouraged to be informed, to share their

concerns and suggest promoting activities to encourage caregivers to actively engage with PwD to minimise the challenges of care. However, in the case of the current study, caregivers expressed the need to share their concerns, but HCP either did not have adequate time due to increased workload or were not interested in listening to caregivers. However, as previously mentioned, I did not explore the views and perceptions of the formal caregivers in this thesis, this could be explored further in future research. Findings suggest that caregivers would benefit from an integrated care pathway with a complete care package for both PwD and family caregivers, which is coordinated through a single, designated point of contact rather than directing one service to the other (e.g. create combined clinics to treat dementia and other comorbidities, and consultations for health care needs of both the PwD and the main caregiver in the same clinic). In addition to creating combined clinics, the literature suggests a variety of other integrated care pathways implemented in HIC in dementia management. These include: integration between hospital and other private and public institutions such as charity, non-government organisations (NGOs), access to hospice or dementia-friendly elderly care homes and support groups (Jansen *et al.*, 2009; Schoenmakers *et al.*, 2010; Xiao *et al.*, 2014), integration of both pharmacological and non-pharmacological treatment aspects such as counselling, psychological support, stimulation programmes (Etters, Goodall and Harrison, 2008; Brodaty and Donkin, 2009; Gavrilova *et al.*, 2009; Zarit, 2011; Kim *et al.*, 2012). The current study did not reveal any information on these aspects.

Findings suggest that the HCP can take a leading role in establishing integrated dementia care services that links hospital and the primary and community care

settings. Caregivers of the current study preferred HCP (particularly nurses) visiting their homes, having support from volunteer groups in caregiving activities in order to minimise their daily challenges of care (e.g. transport issues, lack of confidence and full-time commitment in care). A good example from HIC to support the applicability of this finding is the eight pillars community model for dementia management in Scotland. This model consists of skilled designated professionals (the dementia practice coordinator) who leads the care, treatment, and support to PwD and caregivers, and coordinate access to all the other pillars (PwD, caregivers, care environment, community, professional and therapeutic interventions) (Kinnaird, 2010). Evidence from HIC indicates the positive impacts of such support programmes and interventions for supporting the caregivers with coping, managing anger, reducing caregiver distress or burden, and skills training (Ostwald *et al.*, 1999; Coon *et al*., 2003; Gitlin, Jacobs and Earland, 2010; Beinart *et al*., 2012). Interventions to alleviate caregiver burden has shown improvements in quality of care, delayed institutionalisation and better caregiver health (Etters, Goodall and Harrison, 2008; Beinart *et al.*, 2012; Jennings *et al.*, 2016). Comparatively, studies in LAMIC also report positive impacts from several interventions to promote community-based dementia care, therefore, it is possible to apply such approaches in the current setting as well. For example, Prince *et al.* (2009) recommend packages of care for LAMIC including provision of information for PwD and caregivers, public information campaigns, community case findings, promoting access to general health care and continuity of support. The 10/66 Dementia Research Group reports that training sessions for community health workers in LAMIC regions were very effective in the early diagnosis of dementia in the community (Prince *et al.,* 2007). Reynolds (2009) writes that a properly trained

professional can coordinate formal and informal care, provide therapeutic relationship for PwD, main caregivers and family members and provide a more holistic, person-centred care throughout their journey from diagnosis of dementia to end of life. Caregiver education and training intervention sessions implemented by trained community health workers were successful in empowering informal caregivers and improved community-based dementia care in LAMIC countries (Gavrilova *et al.,* 2009).

9.3.5 Section conclusion

Findings of the current study revealed that the caregivers' views, perceptions and experiences on dementia and caregiving were influenced by their own explanatory models which were shaped by the religion, culture, and society as well as by caregivers' personal values, beliefs, attitudes and experiences. Findings also revealed that the caregivers of this small study context held different perspectives when conceptualising the meanings of dementia and caregiving. These differences largely influenced caregivers' experiences including their illness perceptions, identification of causes of dementia symptoms, help-seeking behaviour, selection of care pathways for home-based management of dementia, their care needs and expectations as well as how they coped with the issues and challenges of caregiving. Their personal and family values, cognitive schemata (thoughts, beliefs, attitudes and assumptions) and experiences were mostly unique. However, some caregivers held onto commonly shared beliefs and rituals which appeared popular and held widely by the society, culture and religion in the study context. In line with the concepts of interpretive phenomenology, findings emphasised that caregivers cannot abstract themselves from their personal values, family traditions and

broader socio-cultural context when conceptualising meanings to their lived-experiences of caregiving.

In conclusion, the current study revealed a dynamic process of caregiving which represented both positive and negative aspects of care among family members who cared for PwD. Most caregivers found positive meaning in their caregiving such as togetherness, enhanced understanding of others with problems, discovering inner strengths, resilience in long-term care, happiness and joy, mastery of tolerance and coping, realisation of the impermanence of life, personal growth and self-acceptance, through the caregiving experience. However, the positive aspects of home-based informal dementia caregiving are less explored in the literature when compared to negative aspects. These findings will therefore extend the existing literature. The current study also reports the negative aspects of caregiving such as distancing relationships, guilt, suffering, burden, role captivity or loss of freedom of the caregiver and depression caused by increasing responsibility alongside the severity of condition and dependency of the PwD and family or social pressure. Further, findings affirm the existentialist ideas that the critical life experiences of the informal caregivers gave them an opportunity to search for meanings of caregiving and purpose of life. The process of finding meaning and seeing the *'positive aspects of caregiving'* instead of *'suffering'* was their choice based on pre-existing values, beliefs, responsibility for right action and conduct of the individual caregiver.

Findings indicated how the caregivers' views and experiences evolved throughout their journey. The caregiving process was a unique experience and was liable to change over time in response to number of factors in the individual caregiving

situations. The consequences of long-term caregiving included a continuous and dynamic pattern of changing relationships between the PwD, caregivers, family members and wider social networks. In general, findings of the current study agree with the critical aspects of dementia caregiving reflected in the Caregiver Identity Theory by Montgomery and Kosloski (2009), which explains 'caregiving career' as a journey that includes a 'series of transitions' that result from changes in the context of caregiving and in personal norms and values that are grounded in family, society and culture. Key areas highlighted in the thesis were:

(1) Conceptualisation of the meaning and purpose of caregiving included both positive and negative aspects,

(2) The caregivers varied greatly in several characteristics (e.g. gender, duration of caregiving, responsibilities and tasks involved, level and type of support received and the perceptions and experience towards their caregiving role,

(3) Caregiver burden was multidimensional and influenced by many factors, such as caregiver characteristics (age, gender, health), change in the relationship between the PwD and caregiver, or broader sense of burden driven by socio-cultural influence,

(4) The caregivers experienced changes in their role and 'identity discrepancy' within the 'dyadic relationship changes' over time with increased severity of BPSD and dependency of PwD,

(5) Caregivers held different views (explanatory models) towards illness and caregiving, care pathways they were willing to use; they did not use care models, treatments or services that they perceived not helpful.

Existing literature is consistent with the findings of current study. For example, Wilson (1989), from a grounded theory study, identified the meaning of the caregiving journey through several stages: *'noticing, discontinuing and normalising, suspecting, searching for explanations, recasting, taking it on, going through it and taking it over*'. Similarly, Keady and Nolan (1994) developed a longitudinal model using grounded theory to describe the caregivers' journey: *'building on the past, recognising the need, taking it on, working through it, reaching the end, a new beginning'*. These studies extend the caregiving literature by adding light on the caregiving process. However, they lack the evidence concerning the ideographic, individual views and experiences during the caregiving journey. Therefore, the novelty of current study is the findings concerning the perceptions and lived experiences of individual caregivers along their caregiving journey.

It appeared that the caregivers experience a range of issues and challenges at various stages of their caregiving journey. Figure 9.1 illustrates the overview of the factors that contribute to these issues and challenges of caregiving.

Despite the widely accepted westernised views on dementia caregiving (e.g. medical model of care, burden and distress), the current study also suggests the importance of integrating the socio-cultural beliefs and healing practices with westernised medical care models in order to address caregiver concerns and to increase the effectiveness of home-based management of dementia care.

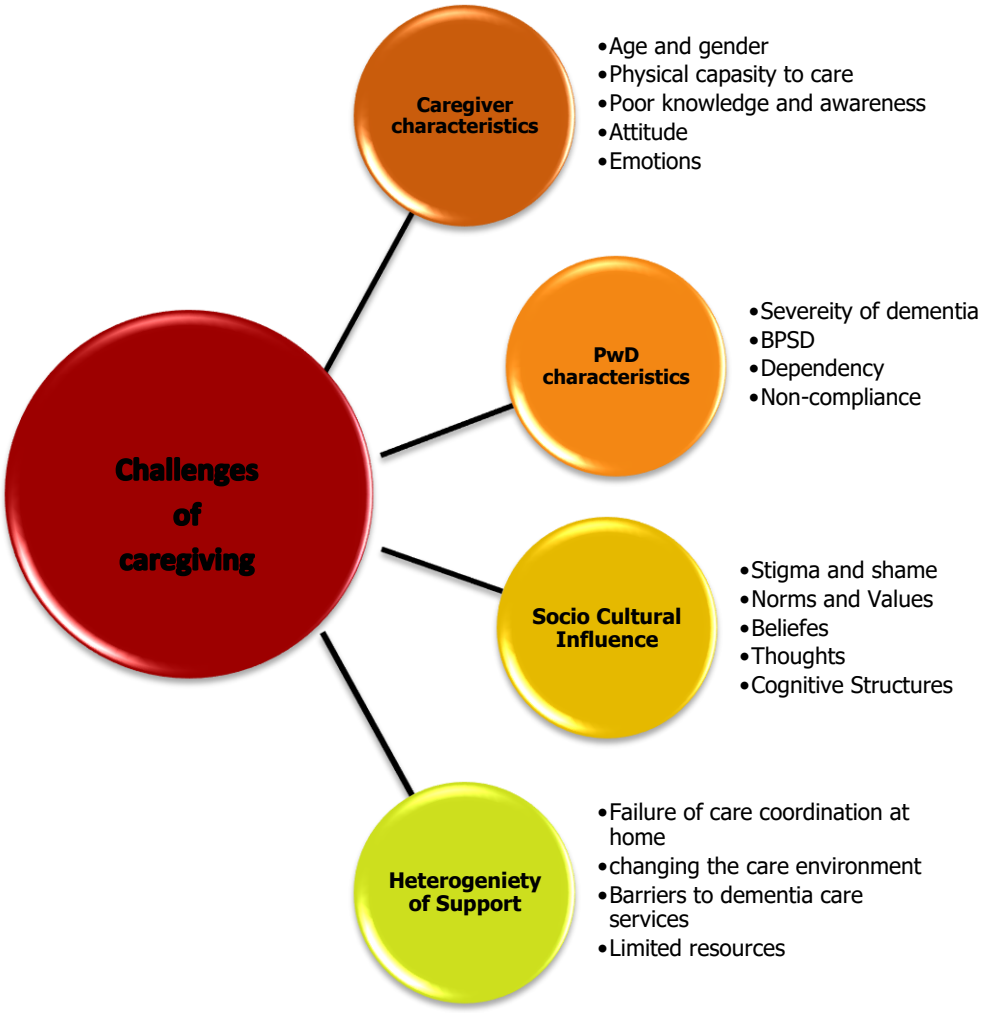

Figure 9.1: Factors contributing to challenges of caregiving

9.4 Implications and recommendations of the study

9.4.1 Implications for policy and practice

Findings indicated that informal dementia caregivers held a range of explanatory models of dementia and caregiving (e.g. bio-medical, social, religious or supernatural) with very disparate views, perceptions and experiences of dementia and caregiving. However, it appeared that the provision of formal care is singularly principled on the westernised, medical care model (as described in Chapter Eight, Section 8.2) and it does not fit effectively in the management of dementia in the Sri

Lankan context due to the influence of widely accepted cultural and religious practices in dementia care. Integration between the Westernised, medical care model and non-westernised, traditional or complementary care models alongside the caregiver explanatory models will be more beneficial in the management of dementia in the study context.

According to findings, there is a significant gap in existing services for PwD and their caregivers; current health services did not address the caregivers' financial, psychological and socio-cultural issues related to home-based caregiving. Findings indicate that integrated care pathways to support PwD and their caregivers (for example, community-based screening for dementia, interventions to raise dementia awareness and empower family caregivers, home visits by HCP and community interventions such as day-care or volunteer care services) are currently unavailable in Sri Lanka. Establishing an integrated care pathway for PwD and informal caregivers will positively impact quality of life of PwD and their caregivers. In support of this, Fernando *et al.* (2017) also highlight the need for shifting the existing bio-medical model to a bio-psycho-social care model when providing mental health care to people in Sri Lanka. It is also important to utilise a person-centred care approach to identify and address the individual support needs of the caregivers.

Findings highlighted a significant gap in dementia awareness and information disclosure among study participants resulting in delays in diagnosis and seeking medical support, stigma and misunderstandings of symptoms of dementia and increased caregiver burden. The MoH and HCP can utilise these insights to raise dementia awareness among people in Sri Lanka. Possible interventions aimed at

raising dementia awareness and reducing stigma could be: writing a guide to family caregivers in their native language (i.e., Sinhala and Tamil) and facilitate health promotion activities among the lay communities. Evidence report that the quality of lives of PwD and caregivers can be improved and health care costs of dementia can be reduced by establishing interventions for timely diagnosis, raising dementia awareness, encouraging home-based care and supporting family caregivers (Thompson *et al.*, 2007; Dias *et al.*, 2008; Jansen *et al.*, 2009; Robinson, Tang and Taylor, 2015; Villapando, 2015; Livingston *et al.*, 2017). A community centred health promotion intervention related to maternal and child health has shown positive results in rural communities in Sri Lanka (Guruge *et al.*, 2017; Guruge, Dharmaratne and Gunathunga, 2018). Similar approach can be used to raise dementia awareness and reduce stigma among lay communities in the study context. For example, Guruge *et al.* (2018) report that it is possible to train volunteer lay community groups such as elderly societies, women's welfare groups and funeral welfare societies (a volunteer social support group formed by people to support families during a funeral), and involve them in educating wider community. Guruge *et al.* (2018) state that such health promotion interventions are effective in addressing complex problems (such as stigma) and making sustainable changes at household and community level as the empowerment comes within the community.

With the implementation of the 'Declaration of Alma-Ata' in 1978, the WHO identified primary health care as an essential part of health with its main objective 'to have better health for all'. Minimising social disparities, service delivery reforms, integrating health into all public policies, leadership reforms and high

stakeholder participation were the key fundamentals in this approach. However, changing demographics and epidemiological transitions in Sri Lanka have exerted pressure to revitalise the primary health care (PHC) setup. Most secondary and tertiary health care facilities are overcrowded, whereas many PHC facilities are underutilised (Senanayake *et al.*, 2017). In addition, the concepts of family medicine and home-based care need to be integrated into PHC practices in order to strengthen the current healthcare system (Fernando, Suveendran and De Silva, 2017; Senanayake *et al.*, 2017). In order to strengthen the PHC system with comprehensive community-based and family-focused care in Sri Lanka, several key reforms were identified recently as the priority concerns (MoH, 2016a). The strategies to be implemented include: task shifting of PHC workers to combat non-communicable diseases (including dementia), re-model and re-orient primary medical care units in the country, establish a 'general practitioner (GP) system' to link the preventive and curative PHC services at divisional level, develop guidelines to establish lifestyle modifications, community screening for non-communicable diseases, and introducing personal health records and referral cards for all citizens, promote personalised and family centred care, and introduce electronic medical record systems to minimise compartmentalisation of treatment and to improve the continuum of care (Annual Health Bulletin, 2016; Senanayake *et al.* 2017).

In light of the findings and suggestions made by the study participants, there are three main avenues of potential interventions: (1) empower caregivers by improving their knowledge, caregiving skills and coping skills, (2) raise dementia awareness in communities, and (3) develop an integrated, community-based formal care system with workforce for managing dementia in the homes of PwD.

However, the current thesis is based on a small-scale study and this is only a starting point. More research is needed before implementation and making changes to the current dementia care policy and practices at a national level.

9.4.2 Implications for future research

Findings of this thesis offer insight into home-based dementia caregiving experience of a group of family caregivers in Sri Lanka. Further, the systematic review (Chapter Three) revealed the dearth of dementia research activity in the context. These findings illuminate topics for future exploration. Future research could focus explicitly on the caregiving journey and the changes over time could be further explored through a longitudinal research design. I also suggest further investigations to establish the costs and benefits of traditional or complementary care practices, and also to evaluate the impact on coping by caregivers (such as caregiver burden and bereavement experience) as there may be very useful aspects of each approach that could be integrated with the medical model practiced in formal care setting. The current study did not focus on formal caregivers.

A further recommendation is to conduct studies that focus on exploring views, perceptions and experiences of formal and professional caregivers. This will help understand issues, challenges and service gaps experienced by formal caregivers and will enable comparisons with family caregivers' views and experiences.

Findings indicate the need and importance of raising dementia awareness (among PwD, caregivers, family members and the public) and professional support to improve quality of care and quality of life of both PwD and their caregivers. The information on support needs of caregivers and suggestions to overcome their current issues and challenges are important to initiate discussions among relevant

authorities for future planning to address their needs. For example, findings of the current study highlight the importance of adapting culturally sensitive care models rather than following the westernised bio-medical care model. Further, the voices of study participants can help identify reasons for poor compliance in dementia management (e.g. reluctance for clinic attendance and poor medication adherence) and identify how to educate the people with dementia and their families effectively. Culturally sensitive, locally appropriate intervention studies can be designed to raise dementia awareness, to minimise stigma, and to support PwD and their family caregivers. Findings indicated a greater need of raising awareness among caregivers, family members and the public in general. I recommend establishing a Patient and Public Involvement and Engagement (PPIE) group from the study participants (as most of them expressed willingness) and initiate awareness programmes among them as a pilot and later extend such programmes as a health promotion activity within the context. PwD and caregivers can be supported by establishing support groups within the community. A caregiver support group could be started from the study participants based at the IRD. Similar to 'Dementia friends' in the UK, in Sri Lanka we can establish a programme using volunteers to raise awareness among people and to support PwD and their caregivers. As carried out in previous studies by Guruge *et al.* (2017, 2018) lay community groups can be trained and utilised in order to identify early signs and symptoms of dementia, to raise public awareness on dementia and to support PwD and their families. University students (e.g. medical, nursing and health promotion undergraduates), school children and professionals who work closely with older adults can also be educated and use as messengers to raise public awareness through this programme.

9.5 Strengths and limitations of the study

9.5.1 Strengths

The comprehensive systematic review on dementia research activity in Sri Lanka helped the identification of the research gap, priorities and the importance of dementia research in the study context. There were only a few studies reporting on dementia prevalence and care management including just one survey on caregiver burden. Findings indicated a need for high-quality research, including empirical research. The current study is the first qualitative study to explore the views and experiences of informal dementia caregivers in Sri Lanka.

There were many strengths in selecting the phenomenological approach for this study. IPA as a methodology is not a 'simply descriptive' approach (Smith, Flowers and Larkin, 2009); it consists of a phenomenological requirement to understand and 'give voice' to participants and an interpretative requirement to contextualise and 'make sense' of the claims (Larkin, Watts and Clifton, 2006). The research methods embedded within the phenomenology (discussed in Chapter Four, Section 4.2) enabled me to carry out a high-quality in-depth exploration of the studied phenomenon. The combination of one-to-one main caregiver interviews and group family interviews allowed me to gain different perspectives including personal and shared meanings and experiences of caregivers and sometimes the PwD. I was able to access a comparatively large number of participants (20 families) and conducted 14 individual interviews and 12 group interviews among them. These in-depth, semi-structured interviews were a source of rich information.

The IPA method allowed me to depict individual participants' thoughts, beliefs, perceptions and attitudes towards dementia and experience of caregiving in an ideographic perspective; it also involved a highly intensive and detailed analysis (Larkin, Watts and Clifton, 2006; Smith and Osborn, 2008). Data analysis and interpretations were comprehensive and in two stages. In the first stage of analysis transcripts were analysed and interpreted while being reflective and sensitive to the individual voices of each participant (idiographic analysis) and in the second stage, the patterns across the entire data set was derived (Ali and Bokharey, 2015; Smith, 2017). This process allowed 'sense-making' of the participants' world and enabled reporting unique, very revealing and descriptive claims of each individual caregiver in a thematic form (Smith and Osborn, 2008; Smith, Flowers and Larkin, 2009).

9.5.2 Limitations

Study participants were recruited via a purposive sampling method and they are not likely to represent the general population in the context. Although I recruited a broader range of participants in terms of duration of caregiving as well as the PwD's severity of dementia, this study is limited by a lack of ethnic and religious diversity. For example, I was not able to access any Tamil- Hindu or Muslim- Islamic caregivers; the majority of participants were Sinhala- Buddhists and there were a few Sinhala- Catholics. It limited the opportunity to explore broad perspectives on religious and traditional beliefs, healing methods and related caregiving perspectives. Therefore, most of the interviews included Buddhist concepts when describing caregivers' views, perceptions, and experiences towards dementia and care provision. A sample made up of people of different ethnic groups would

increase the representativeness of the data. This could form the basis for a later study. Inclusion of future research with additional variables such as ethnic and religious diversity might further illuminate the findings.

It is also important to note that except for one family, all the other families were recruited from one of the dementia clinics conducted in the study setting. Consequently, although this group of caregivers were able to reflect on pre-diagnosis experiences, it leaves unspoken the views and experiences of those who provide home-based care PwD who had not been clinically diagnosed with dementia. Perhaps the illness perceptions, caregiver identity and issues and challenges experienced by such caregivers and PwD could be different. Studies show that socio-economic and cultural influences, education, awareness of the caregivers influence health care access (Bieber *et al.*, 2017, 2019; Stephan *et al.*, 2018); there may be a number of people residing in the community without any formal diagnosis and not have engagement with health services at all (Jutlla, 2015b; Hossain *et al.*, 2018; Bieber *et al.*, 2019). More research is required among these groups.

9.6 Reflections

This section links to my reflections on methodological concerns described in the methodology chapter. As described in the methodology chapter (Section 4.2.6.4), I allowed flexibility during the interviews in terms of breaks, and discussions within the family members. I also used my interpersonal and communication skills to maintain the smooth flow of interviews. Good interviewers are flexible and follow up on unanticipated issues (Smith and Osborn, 2003; Braun and Clarke, 2013). I

felt confident and organised during the interviews as the topic guides helped me to be prepared and think of possible difficulties in advance.

Family members gained knowledge and a better understanding of each other's perspectives as a result of taking part in the interviews. Group interviews were similarly useful for the participants to understand the illness and concerns of each family member about caregiving. Some of the interviews were more of a discussion among family members sharing their feelings towards each other. It helped family members to increase awareness and realise each other's role in caring for the PwD. Many participants considered that the interviews were a good opportunity for them to raise their awareness of dementia and caregiving. As reported by many participants, it was during the interviews that they first started thinking about the meaningfulness of their actions. I believe, their understandings will inspire other family members and dementia caregivers who are struggling to find what caregiving means to them.

I used my identity as a mental health nurse when introducing myself to the participants and that helped me to develop rapport with them. When providing information, I used my knowledge as a nurse, evidence read in recent dementia literature and my own experiences as a family caregiver for a PwD and as a nurse. I felt the caregivers tended to believe and accept the information as it was coming from a health professional. I think my caregivers were oriented to me predominantly as an HCP, but also as a friend who had similar experiences. I also felt that I was accepted by the participants during the interviews as they were comfortable to reveal their stories and disclosed rich information for the questions asked during the interviews.

After every interview, I spent an additional hour or two with the family having an informal post-interview chat as they requested more information and psychological support for the caregivers when necessary. Every interview was followed by educating main caregivers and family members on their request, it was useful to raise awareness among them. Caregivers who first denied the condition or refused to acknowledge BPSD tended to change their negative attitudes and thinking patterns following the information received during and after the interview.

Many caregivers found the information was very useful to educate other family members and neighbours about the illness, as it could help to resolve disputes caused by misunderstandings, which also helped to enhance their positive attitudes and support. Some of the caregivers were willing to volunteer in further studies and in future public awareness programmes to receive more information and share their experience among others. In general, all participants thought raising awareness is the key to the provision of good quality care and receive satisfaction after long term caregiving. Some caregivers affirmed that they will support and join me to share their stories with the public if I could arrange an education programme in their community.

My personal experience being a family member of a PwD and as a formal caregiver for PwD led me to see first-hand how devastating dementia and caregiving can be. An 'insider researcher' shares 'an identity, language, and experiential base' with the study participants (Asselin 2003). On a positive note, I always had a passion about my study which helped me remain committed to the study despite all the hurdles. My understanding, empathy and sensitivity to the discussed matters and

the perceptions of the caregivers helped them to be more open during interviews. Therefore, the entire data collection process felt natural to me; it also had a positive impact on my personal values and self-development as a human being. However, as I previously described in the methodology chapter (See page 138), there were practical challenges in being an insider researcher. I overcame the potential biases by conducting my research ethically and systematically with an academic interest in the area of study, through bracketing my judgements or assumptions that could influence the data analysis process and interpretation of findings (Asselin, 2003) and reflections. Dwyer and Buckle (2009) state that on reflection, researchers can share experiences, opinions, and perspectives with the participants, but sometimes can also see themselves as outsiders instead of as insiders.

Reflections on the challenges I experienced

My expertise as a nurse and a counsellor was utilised to provide health education and psychological support to caregivers when necessary. For example, I encouraged them to communicate their concerns to me, and sometimes to discuss with other family members after interviews. I also had to mediate in explaining the caregiver needs and importance of support to family members as requested by the caregivers. I also directed two main caregivers who appeared to experience depressive symptoms to a consultant psychiatrist at their request. Though it was not my role as a researcher, I made a conscious choice to provide health education and support these caregivers. I hope I managed to make a difference in my participants' lives by giving them a chance to reflect on their own experiences in light of this new knowledge and understanding.

The caregivers first knew me as a researcher and a nurse by profession by the time I recruited them for the study. However, after interviews I revealed my personal experiences of caregiving for my uncle and my counselling identity if it was required. I believe, the caregivers accepted me as an expert in dementia information and as a friend to disclose their concerns, grievances and even very personal matters. After interviews, during my stay in Sri Lanka, some caregivers used to contact me using the number I gave them (during recruitment) and updated me regarding the PwD and changes happened in their lives after interviews. I even helped one caregiver to find her demented father when he went missing and visited one PwD's funeral after the data collection. I understand my limitations and professional boundaries as a researcher, but as an act of reciprocation I decided to be involved and to support them. However, sometimes I felt these interactions were challenging and emotionally draining, I remember struggling to control my tears while listening to caregivers' sensitive stories. Therefore, I regularly communicated with the supervisors to maintain my personal wellbeing during the data collection process.

I felt that conducting some of the main caregiver interviews was a challenge when other family members were around as they overheard or intervened in the interview causing distractions to the flow of discussion. One main caregiver requested to reschedule her interview because she did not feel that she could talk honestly and openly in front of her family members. Working with a large sample size was challenging as I had to transcribe and analyse a large number of transcriptions which was exhausting and time-consuming. However, I analysed my data (as described in section 4.2.8.2) following the guidelines given by Smith *et al.*

(2009). The next challenge was to translate the study documents and transcripts while keeping to the original meaning of certain words and phrases used by participants. However, only five transcripts were translated into English for supervision and examination purposes.

9.7 Conclusion

This thesis illuminated several key aspects of views, perspectives and experiences of a group of informal dementia caregivers living in a semi-urban town in Sri Lanka, which provided insights on home-based, informal caregiving for PwD. This study revealed, the importance of one's personal values, socio- cultural norms and religious beliefs in the way an individual conceptualises the meaning of dementia, the causes of dementia, and the caregiving experience. Caregivers' lack of understanding and awareness of dementia, belief systems that are influenced by society, culture and religion all have a significant impact on the caregiver role, caregiving patterns, support systems for PwD and caregivers, consequences of caregiving, and also on coping by the caregivers.

Socio-cultural and religious differences also inform the need for more directed and localised assessments to address the care models of dementia, the models of informal caregiving and the needs of PwD and their caregivers. This knowledge may be used to inform practice and policy regarding the essential components and processes of in-home and community-based dementia services to enhance the quality of life of PwD and their informal caregivers.

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Appendices

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- *Appendix 03-A: Ethics Committee Correspondence – Keele University, UK*
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Appendix 01: Systematic Review Protocol

Arthritis Research UK Primary Care Centre

Systematic Review Protocol & Support Template

This template is primarily intended to help you plan your review in a systematic way. A copy of this completed form will be available via the intranet to help others carrying out reviews in the future and to avoid duplicating work already undertaken in the Centre. Keeping a record of all the reviews will also assist in planning the work of the Centre and ensuring adequate methodological support. Not all the information will be relevant to every review. However, items can be adapted to fit the type of review that is being undertaken.
Please complete the form in as much detail as possible for your review and email to Opeyemi Babtunde, o.babatunde@ keele.ac.uk

Title of the review	A systematic review on dementia research activity in Sri Lanka
First reviewer	Kalpani Abhayasinghe
Team of reviewers	Kalpani Abhayasinghe Lasith Dissanayaka Dr. Paul Campbell Dr. Benjamin Saunders Prof. Athula Sumathipala
Supervisor/Project PI	Prof. Athula Sumathipala Dr. Benjamin Saunders Dr. Paul Campbell
Clinical Portfolio Group	N/A
Project title (if different from review title)	Views and experiences of informal caregivers of older adults with dementia in Sri Lanka: a Phenomenological Study

Support – please state if advice/training or personnel required at each stage	
SR overview	Kalpani Abhayasinghe will carry out the systematic review overview with the advice and support of Prof. Athula Sumathipala, Dr. Benjamin Saunders, Dr. Paul Campbell, Dr. Opeyemi Babatunde and Dr. Jo Jordan

Protocol development	See above
Literature searching	Kalpani Abhayasinghe will create the search terms with the support of Prof. Athula Sumathipala, Dr. Opeyemi Babatunde and Jo Jordan regarding the choice of search filters and following keywords. Dementia, Alzheimer's disease Cognitive impairment Elderly people, old age Caregiving Caregivers (i.e formal or informal caregivers (family members, friends, neighbours, health care professionals, ect.) Sri Lanka
Quality appraisal	Kalpani Abhayasinghe will perform the quality appraisal using a check list or standardised assessment tools for quantitative and qualitative studies (eg: joannabriggs critical appraisal tools - http://joannabriggs.org/research/critical-appraisal-tools.html) with the support of Opeyemi Barbatunde. Any disagreement about the quality of papers will be resolved by Prof. Athula Sumathipala. The assessment of risk of bias will be performed by Kalpani Abhayasinghe with the support of Prof. Athula Sumathipala and Dr. Opeyemi Babatunde.
Data Extraction	Kalpani Abhayasinghe, Lasith Dissanayaka and Prof. Athula Sumathipala will carry out data extraction
Synthesis	Kalpani Abhayasinghe with feedback from Prof. Athula Sumathipala, Dr. Benjamin Saunders and Dr. Paul Campbell will carry out the review synthesis.
Writing up	Kalpani Abhayasinghe will write up the systematic review. Draft feedback and correction suggestions will be offered by Prof. Athula Sumathipala, Dr. Benjamin Saunders and Dr. Paul Campbell

1. **Background to review**

Brief introduction to the subject of the review, including rationale for undertaking the review and overall aim

Dementia is a global health concern. It is considered to be one of the most burdensome conditions of later life. 66% of elderly people with dementia live in developing countries (Prince *et al.*, 2012) but the evidence suggests that only 10% of research is carried out in those developing countries on the subject (Patel, 2007). According to World Bank Report (2006), in the coming years Sri Lanka will experience the fastest ageing population among South Asian countries. Estimated dementia population in 2015 in Sri Lanka is at least 150,000, and in 2050 that figure will rise to 463,000 (Wijeratne, 2015).

Dementia is a progressive, chronic, irreversible condition that impacts on the person's cognitive ability, behavioural and psychological expression, and activities of daily living to such an extent that the person with dementia may need round the clock caregiving over several years, the majority of that time within an informal caregiving setting. Informal caregiving is mostly provided by close family members, neighbours, friends or non-trained individuals. Even though caregiver burden and challenges are universally reported, current information and research on the caregiver experience is lacking in Sri Lanka as with other developing countries. Information at a localised level is important because emerging evidence suggests different models of care exist within different cultural contexts. For example, Prince et al (2012) shows that the majority of the studies and care giving models on dementia predominantly come from developed western countries. Also the studies have shown significant differences in model of care and how caregivers perceive the caregiving role for those with dementia in different countries (Wijeratne, C., 2015; Wang et al., 2014, Pattanayak et al., 2010).

Further to that the studies carried out in other countries report that there is a significant impact of culture and ethnicity in the dementia care-giving. Considering this, it appears clear there is a need to explore how dementia care is provided within a more culturally-specific context. Caregiving for people with dementia is socially, culturally and politically constructed (Wang et al., 2014, Wijeratne, 2015). As the illness progression the responsibility of the caregivers is also increased. Many systematic reviews carried out in other countries in dementia in the aspects of dementia, PwD and caregiver characteristics, effectiveness of interventions and factors associated with caregiver burden (chiao et al., 2015). But no evidence for systematic reviews carried out in Sri Lankan studies.

Therefore, the broad aim of this systematic review is to explore the main dimensions of dementia care in Sri Lanka. This information will inform on dementia prevalence, PwD and caregiver characteristics, and available care models for Dementia. Specific objectives include: to collect and critically appraise the current literature on caregiving for those with dementia within Sri Lanka, conceptualise and group evidence of care models, care approaches and care processes, and explore evidence of caregiver outcome measurement and assessment (e.g. burden, depression, stress) and describe evidence of the factors associated with outcomes (e.g. prognostic factors predictive of burden).

References:

Chiao, C.Y., Wu, H.S., Hsiao, C.Y. (2015) Caregiver burden for informal caregivers of patients with dementia: A systematic review. *International Nursing Reviews.* International coincil for nurses.

Patel V. (2007) Closing the 10/90 divide in global mental health research. *Acta Psychiatria Scandinavia* 115: 257 – 9

Pattanayak R.D., Jena R., Tripathi M. & Khandelwal S.K. (2010) Assessment of burden in caregivers of Alzheimer's disease from India. *Asian Journal of Psychiatry*; 3(3), 112–116

Prince, M., Acosta, D., Ferri, C.P., et al. (2012) Dementia incidence and mortality in middle-income countries, and associations withindicators of cognitive reserve: a 10/66Dementia research Group population based cohort study. *Lencet*. 380: 50 -58.

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Wijeratne, C., (2015) *Dementia Handbook for Carers and Health Care Professionals in Sri Lanka*. IRD

World Bank (2006) Sri Lanka Aging Survey - SLAS, the survey based on a representative sample of Sri Lankan old people). *BMC Research Notes*.3:268.

2. Specific objectives

1. To review evidence of dementia research activity in Sri Lanka
2. To map the output of dementia research activity to assess the current research focus and priorities in Sri Lanka
3. To describe the measures of dementia care management and services within the Sri Lankan context

3. a) Criteria for including studies in the review If the PICOS format does not fit the research question of interest, please split up the question into separate concepts and put one under each heading	
i. Population, or participants and conditions of interest	All quantitative and qualitative research studies conducted in Sri Lanka are to be included if they focus on people with dementia or severe cognitive impairment, and caregiving for dementia. The review strategy will take into consideration all the possible articles related to elderly (or age > 60), dementia, Alzheimer's disease, cognitive impairment and dementia caregiving in Sri Lankan context. Articles meeting the inclusion criteria are to be considered regardless of the publication status and date of publication.
ii. Interventions or exposures	At the beginning of the search we will use a combination of the following groups of search terms in order to retrieve the largest possible number of articles: – Dementia – Caregivers (i.e formal or informal caregivers(family members, friends, neighbours, health care professionals,ect.) – Care models of dementia
iii. Comparisons or control groups	Any
iv. Outcomes of interest	The following aspects of dementia care may be considered as outcomes of interest: – evidence on care models for dementia – the course of the disease – the definitions of caregivers for those with dementia, and how the caregiving role is described within Sri Lankan context – the measurements used to assess dementia caregivers within the Sri Lankan context
v. Setting	This review will focus on all the aspects of dementia, care models and caregivers in Sri Lanka, irrespective of their age, gender, training or period of caregiving.
vi. Study designs	This review will include all the studies published at present regardless of design. This enables us to review all the related articles published up to now since the available literature is minimal.

3. b) Criteria for excluding studies not covered in inclusion criteria Any specific populations excluded, date range, language, whether abstracts or full text available, etc.
Studies involving HIV related dementia, early onset dementia and acquired immunodeficiency syndrome dementia complex will be excluded.

4. Search methods	
Electronic databases Please list all databases that are to be searched and include the interface (eg NHS, EBSCO, etc) and date ranges searched for each	❖ The search will be carried out using the following databases without any limit for date ranges. – EBSCO – CINAHL Plus with Full Text – EBSCO – MEDLINE – EBSCO – PsycINFO - EBSCO – EMBASE – AMED ❖ Additionally, other health databases may be screened: – The Cochrane Central Register of Systematic Reviews and Controlled Trials – Web of Science (It is an online subscription-based scientific citation indexing service maintained by Thomson Reuters that provides a comprehensive citation search. It gives access to multiple databases that reference cross-disciplinary research, which allows for in-depth exploration of specialised sub-fields within an academic or scientific discipline). – SLJOL (SLJOL is a database of journals published in Sri Lanka, covering the full range of academic disciplines. It is managed by the National Science Foundation of Sri Lanka and was developed in collaboration with INASP) Kalpani Abhayasinghe and Lasith Dissanayaka will perform the search.
Other methods used for identifying relevant research I.e.; contacting experts and reference checking	❖ The authors of published papers will be contacted to conduct a comprehensive search looking for unpublished or “grey literature.” ❖ The references of all the retriewed articles will be read to identify any relevant cited articles that were not identified in the review.

Journals hand searched If any are to be hand searched, please list which journals and date searched from, including a rationale.	❖ MD and MSc thesis submitted to Post Graduate institute of Medicine (PGIM) – Sri Lanka will be looked in to find the related information. ❖ Records of ongoing research, conference proceedings and theses will also be looked for unpublished research findings.

5. Methods of review	
Details of methods Number of reviewers, how agreements to be reached and disagreements dealt with, etc.	An initial abstract screening stage will be applied to all identified articles and those not meeting the inclusion criteria will be removed. There will be two reviewers performing the selection of the papers to be included in the systematic review, Kalpani Abhayasinghe and Lasith Dissanayaka. If the reviewers disagree if a study meets the inclusion criteria, the paper will be assessed by another reviewer (Prof. Athula Sumathipala/ Dr. Paul Campbell), until an agreement about the inclusion/ exclusion of the study will be reached. After the first phase, all full text articles of the studies considered to meet the inclusion criteria will be read and then retained or excluded. A record of the decision for each article will be kept and a list for the excluded articles will be made, including the reasons for exclusion. A flow chart showing the number of studies/ papers remaining at each stage will be made, according to the PRISMA criteria. The extraction of the data will be undertaken at the same time of the quality assessment of the studies. For the extraction of the data a form will be used. The form is subsequently described in this protocol. The quality assessment checklists that will be used is described in the section below. If information from unpublished studies is obtained, it will be subjected to the same methodological evaluation used for published studies.
Quality assessment Tools or checklists used with references or URLs	Joannabriggs critical appraisal checklists will be used for the quality assessment of the studies. The each checklist include 7 –11 questions, depending on the types of study design. And the checklists will cover the full range of study designs may include in the review (http://joannabriggs.org/research/critical-appraisal-tools.html) The quality assessment will be performed by the main reviewer (Kalpani Abhayasinghe), and cross checked by the second reviewer (Dr. Paul Campbell). The third reviewer will be used to resolve any disagreements (Prof. Athula Sumathipala).
Data extraction What information is to be collected on each included study? If databases or	During the data extraction the following information will be extracted from the papers and they will be put in an word or Excel table: General information ❖ Date of data extraction ❖ Record number ❖ Article title

forms on Word or Excel are used and how this is recorded and by how many reviewers	❖ Authors ❖ Year of publication ❖ Aim of the study ❖ Study design ❖ Study setting ❖ Study inclusion/exclusion criteria ❖ Recruitment procedures used ❖ Sample size ❖ Response rate ❖ Information about non-responders ❖ Age, Gender, Incidence rate and prevalence rate of Dementia ❖ Dementia type ❖ Data collection tools used in study ❖ Caregiver burden measures ❖ Risk factors for caregiver burden - PwD caracteristics/ Caregiver characteristics ❖ Type of analyses performed (Qualitative or statistical) ❖ Quality assessment ❖ Results ❖ Conclusions/ Recommendations/limitations ❖ Personal notes and Remarks (e.g. limitations of the study) The data extraction will be performed by Kalpani Abhayasinghe and Lasith Dissanayaka, and cross checked by the second reviewer (Dr. Paul Campbell). The third reviewer will be used to resolve any disagreements (Prof. Athula Sumathipala).
Narrative synthesis Details of what and how synthesis will be done	The narrative synthesis will include the following phases: ❖ Developing a preliminary synthesis of findings of included studies ❖ Exploring relationships within and between studies ❖ Assessing the robustness of the synthesis The initial descriptive summary of reviewed articles will include a table with information about the author, year of publication, study design, sample size, summary of participant characteristics, dementia type, data collection tools used, outcomes and outcome measures and also an indication of study quality or risk of bias. Then we will include another summary table for studies on caregiver burden including the caregiver type, definition of caregivers, caregiver burden measures, and relationship with the PwD, and risk factors for caregiver burden. Risk factors for caregiver burden will be grouped by PwD and caregiver characteristics. Then it will follow a detailed description of the relationships within and between studies. Idea webbing/ conceptual mapping and visual representation of relationship between study characteristics and results will be used to construct groupings and relationships. For example, we will look for dementia as a

	broader concept and then will look in to care models and the dimensions of caregiving. Care models can be formal or informal. The dimensions of caregiving may include dementia diagnosis/ assessment, impact on PwD/ family and caregiver burden. These dimensions will be based on the outcomes of the studies. Then, the robustness of the synthesis will be appraised through validity assessment using the said appraisal tools. Based on the specific review objectives a critical discussion to address methodologies of the synthesis will be used and will check the synthesis with authors of primary studies. During the validity assessment, the specific measurements and assessments used for PwD and caregivers will be assessed and weighed, giving greater credence to the findings of the most methodologically sound studies according to our quality criteria and the study objectives. This will be made in order to minimise as much as possible the introduction of bias. The narrative synthesis will include a discussion section providing information about the robustness and generalizability of the synthesis. It will include details on the limitations of the methodologies used for the synthesis and their potential influence on the results, evidence used and the possible sources of bias and their influence on the results, assumptions made, discrepancies and uncertainties identified, expected changes in evidence and aspects that may have an influence on implementation and effectiveness in real settings. Moreover, authors of primary studies could be consulted in order to test the validity of the interpretations developed during the synthesis and the extent to which they are supported by the primary data. The authors of the primary studies may have useful insights into the possible accuracy and generalizability of the synthesis as well. At the end of the narrative synthesis conclusion and recommendations will be described based on the outcomes.
Meta-analysis Details of what and how analysis and testing will be done. If no meta-analysis is to be conducted, please give reason.	N/A

Grading evidence System used, if any, such as GRADE	N/A

6. Presentation of results	
Additional material Summary tables, flowcharts, etc, to be included in the final paper	Summary tables showing the information extracted from the articles will be used, as described previously. Flowcharts will be included in the systematic review in order to show the process of inclusion/exclusion of the studies.
Outputs from review Papers and target journals, conference presentations, reports, etc	The results from this systematic review will be shown to internal seminars at the Primary Care Centre, and as part of the annual Post Graduate Symposium besides at relevant national and international conferences. In addition, the information will be used in developing the literature review chapter of PhD thesis of the first reviewer.

7. Timeline for review – when do you aim to complete each stage of the review	
Protocol	**30/08/2016**
Literature searching	**25/09/2016**
Quality appraisal	**10/10/2016**
Data extraction	**20/10/2016**
Synthesis	**15/11/2016**
Writing up	**30/11/2016**

Please send your completed protocol to Opeyemi (see email below) as we would like to put examples on the Intranet.

The systematic review team are available to answer any queries or give advice on completing your review. Systematic review workshops are run at least once a year, or can be arranged on an ad hoc basis if needed by a group. Presentations from previous workshops can be found on the Centre's Intranet.

Opeyemi Babatunde – o.babatunde@keele.ac.uk
Jo Jordan – j.jordan@cphc.keele.ac.uk

Appendix 02: The data extraction form

Data Extraction Form for Systematic Review of Dementia Research Activity in Sri Lanka

Reviewer Details	
Date	
Does the paper meet the inclusion criteria? If no, explain further	
Does the paper meet the exclusion criteria? If yes, explain further	Reasons for exclusion may include irrelevant titles and abstracts (eg: not related to older adults, dementia studies in Sri Lanka), full paper not available, or insufficient data
Study Details	
Study ID	
Study Title	
Author(s)	
Year	
Journal	
Aim and objectives of the study	
Study Aims	
Objectives	
Methodological Characteristics	
Study Design	
Setting	
study inclusion criteria	
Exclusion Criteria	
Follow-up or Study Duration	
Recruitment procedure used	

Sample size	
Response rate	
Data collection Tool(s)	
Method of Data Analysis	
Outcomes	
Outcome Measurements	
Ethical Approval	
Results	
Prevalence n (%)	
Descriptors of the intervention (when the papers are based on intervention studies, that is whether the intervention was with the person with dementia, with family carers or with staff)	
Dementia severity and diagnostic details (dementia type, information about non-responders, demographic information including incidence rate and prevalence rate of dementia)	
Caregiver burden measures (Risk factors for caregiver burden, Caregiver characteristics)	
PwD characteristics	
Details of relevant outcome measures and summary outcome data (Key results)	
Conclusions	
Recommendations	

Limitations of the study	
Domain of the study	Key domains: (Delete the irrelevant, can be more than one domain) Prevalence, Pathophysilogy, Screening for dementia (instrument validation and screening process), Management of dementia (Treatment and Care models), and Caregiver aspects (caregiver characteristics, issues and challenges, etc)
Reviewer Comments (Personal notes and remarks if any)	

Appendix 03: Ethics Committee Correspondence – Keele University, UK

Ref: ERP2307

5th October 2016

Kalpani Abhayasinghe
Arthritis UK Primary Care Centre
RI for Primary Care and Health Sciences
Faculty of Medicine
Keele University

Dear Kalpani,

Re: Views and experiences of informal caregivers of elderly people with dementia in Sri Lanka

Thank you for submitting the above research proposal for ethical review. The proposal was reviewed at the Ethical Review Panel meeting on Thursday, 22nd September 2016 and the Panel commend you on the quality of your submission. The project summary and information for participants is very clear. However, the Panel agreed that the following information / amendments are required before the project can be approved:-

Application form

- The project start date of 15/03/2016 needs to be amended.
- C18 – You will need to complete a risk assessment from, despite the fact that Sri Lanka is your home country.
- D2 - Will PwD and U18's be told that their input will not be used? The harm potentially caused by explicitly excluding them seems greater than letting them take part and you should reconsider this. These participants would be supported throughout by family members and friends, which would buffer their vulnerability.
- D4 - If consent will be sought to use participant data for other researcher, details of this future research need to be included within the Information sheet.
- D8 – You need to clarify how one participant can withdraw from a group interview. You also need to specify what will happen to individual contributions up to the point of withdrawal.
- F3 – The Panel noted that it is a very good idea to only bring encrypted scans of the consent forms and data back to the UK and commend you for this. The Panel recommend that this idea is shared with the other panels as an example of good practice.

Directorate of Engagement & Partnerships
T: +44(0)1782 734467

Keele University, Staffordshire ST5 5BG, UK
www.keele.ac.uk +44 (0)1782 732000

Invitation Letter

- Within the letter, you need to reiterate the fact that the study will not have an impact on the level of care given.

Information Leaflet

- Under the **Will my taking part in this study be kept confidential** section, you need to clarify the fact that only personal data can be kept confidential, otherwise data cannot be published.

Consent Form for Interviews

- The Panel noted that this is an excellent consent form - very clear and straightforward.

I should be grateful if you would address the above points and forward a letter outlining the changes that you have made along with any revised documents to: ERP Administrator research.erps@keele.ac.uk stating **ERP2** in the subject line of the e-mail. (**Note:** please clearly identify in the documentation where changes have been made (e.g. use track changes or use a different colour text for any additional text that is included in the documents, or use a strike through line for any text that has been deleted) and also please remember to amend the version number and date on any revised documents).

Please note that your project is not approved until all of the issues listed above have been addressed to the satisfaction of the Ethical Review Panel and you should not undertake any data collection until approval has been granted. All revisions and re-submitted applications will continue to be reviewed by the initial reviewing ethical review panel.

Your revised application will be reviewed by Chair's action.

The deadline for your response to the Ethical Review Panel is **Tuesday 8th November 2016.** If we haven't received your response by this date, then your application will be rejected and a new application will be required.

If you have any queries please do not hesitate to contact me, in writing, via the ERP administrator, at research.erps@keele.ac.uk stating **ERP2** in the subject line of the e-mail.

Yours sincerely

pp C H Bonnerman

Dr Colin Rigby
Chair – Ethical Review Panel

CC RI Manager
Supervisor

Appendix 03-B: Ethical Clearance Letter – Keele University, UK

Ref: ERP2307

7th December 2016

Kalpani Abhayasinghe
Arthritis UK Primary Care Centre
RI for Primary Care and Health Sciences
Faculty of Medicine
Keele University

Dear Kalpani,

Re: Views and experiences of informal caregivers of elderly people with dementia in Sri Lanka

Thank you for submitting your revised application for review. I am pleased to inform you that your application has been approved by the Ethics Review Panel. The following documents have been reviewed and approved by the panel as follows:

Document(s)	Version Number	Date
Letter of Invitation	1.1	24-10-2016
Information Leaflet	1.1	24-10-2016
Interview Confirmation Letter	1	10-09-2016
Participant Consent Form	1	10-09-2016
Consent Form on behalf of participants with Dementia	1	24-10-2016
Consent Form for minors	1	24-10-2016
Interview Guide	1	10/09-2016
ZBI Questionnaire	N/A	N/A
Flow Charts of Research design	1	10-09-2016

If the fieldwork goes beyond the date stated in your application, **15th March 2019**, or there are any other amendments to your study you must submit an 'application to amend study' form to the ERP administrator at research.erps@keele.ac.uk stating **ERP2** in the subject

line of the email. This form is available via
http://www.keele.ac.uk/researchsupport/researchethics/

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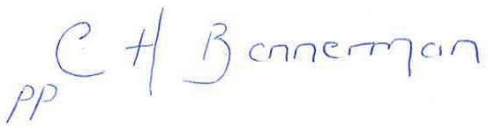
If you have any queries, please do not hesitate to contact me via the ERP administrator on research.erps@keele.ac.uk, stating **ERP2** in the subject line of the e-mail.

Yours sincerely



Dr Colin Rigby
Chair – Ethical Review Panel

CC RI Manager
Supervisor

Appendix 04: Ethics Committee Correspondence – KDU, Sri Lanka

Ethical Review Committee

Faculty of Medicine
General Sir John Kotelawala Defence University
Ratmalana
committee.fomkdu@gmail.com

Tel:+94(0)11-2635268
Fax:+94(0)11-2638660
Email:ethicalreview

30/08/2017

Ms Kalapani Abhayasinghe
Lecturer in Nursing
Dept of Nursing & Midwifery
Faculty of Allied Health Sciences
KDU.

(RP/ 2017/06) "Views and experiences of informal caregivers of elderly people with dementia in Sri Lanka."

The project proposal submitted by you for ethical clearance under the above title was taken up at the Ethical Review Committee meeting held on the 30th of August 2017. We are pleased to inform you that the committee has decided to grant the ethical approval.

Please submit a progress report on the completion of your research project or at the end of one year after starting the project.

Snr Prof Rohini Fernandopulle
(Chair, Ethics Review Committee)
FOM,KDU.

Appendix 05: Interview Guide for main caregiver interviews

Background information

1. To begin, I'd like to get some basic information about you. Tell me about yourself?
   - Age/ gender/ demographic data/relationship with the PwD /family?
   - Occupation?
2. How do you describe your relationship between the person you care for?
   - For how long you have been the main caregiver?
   - How many hours per day you care for the PwD?

How the caregivers defining caregiver role?

3. Tell me about your experience being the main caregiver for this person?
   - How you became the main caregiver?
   - What are the daily routines of caregiving?
   - Any special events to share?
4. How do you feel about your caregiver role? /How do you perceive your life in relation to caregiving?
   - Time involve in care giving
   - Time for yourself
   - Impacts of caregiving/ how does the caregiving has been affected you?
   - Sense of caregiver burden/ responsibility/etc.
   - Physical, Emotional or psychological impacts

Challenges in relation to Caregiving

5. Tell me about the challenges you face when providing care for your loved one? Why do you feel it as a challenge?
   - Any other concern you have in relation to care for your loved one?

Potential Support needs

6. Can you tell me what type of support you get from other family members/ friends/ relatives/ neighbours when caring for your loved one?
   - Involvement in other family members in caregiving/ support from others?/
   - How the work is shared?
   - Do you feel you had the support you needed to do this?

7. What are the available support/ facilities currently available for caregiving?
   - Access to healthcare
   - Treatments
   - Professional support, etc.
8. Thinking of your experience, what do you think it would have been useful/ helpful to improve current health support system in dementia care? What makes you say that?

Prompts:

Could you tell me/ explain a little more about that?
What makes you say so?
Could you give me an example?

Appendix 06: Interview Guide for group family interviews

1. To begin, I'd like to get some basic information about you. (such as your age, education, occupation, relationship to the PwD, ect..). Can you introduce your selves?

2. Could you tell me about your experience when you first learned that your loved one's condition?
   - What was happening around you and your family?
   - How did you/ or family got to know the loved one is suffering from dementia?/ How did the diagnosis make?
   - How did you react to changes/ sign and symptoms/ behaviour of your loved one before diagnosis?
   - What has been your experience of disclosing the condition of your loved one?
   - How did people (family members/ relatives/ neighbours/ friends) respond to your family situation?
   - Tell me about your beliefs/ attitudes regarding the illness? What makes you tell that?

3. Who did you turn for support during this time?
   - Did you seek help from any professional? Why?/ why not?
   - What did you find most helpful/ unhelpful from others around this time? What makes you tell that?

4. What is your role in your loved one's care?
   - How important is it to you to be included in your loved one's care?
   - How does helping your relative/ loved one, or performing the care, make you feel?
   - What sort of a contribution do you feel you make?

5. Tell me about the challenges you face when providing care for your loved one?
   - Do you feel you had the support you needed to do this?
   - Any other support/ needs you require (or any concern you have) in relation to care for your loved one?

Prompts:

Could you tell me/ explain a little more about that?

What makes you say so?

Could you give me an example?

Appendix 07: The invitation letter (English Version)

Institute for Research & Development

Keele University

Study ID Number

Address

Date

Dear XX

The study on Dementia Caregivers in Sri Lanka

We would like to invite you to take part in an interview in order to understand your views and experience of caregiving for your loved one with dementia. I am enclosing an **Information Leaflet** that gives more details.

I will be in touch by phone over the next few days to see if you would be willing to take part in an interview (individual or group interview or both). If you are willing to take part in this, an appointment will be arranged to interview you at a time and place that is convenient to you. This interview will take around one and half hours to complete. You as the main caregiver can participate in individual interview, and the group interview will also be arranged with your family members following the main interview with you. There is **no obligation** to take part.

If you do decide to take part in an interview, the answers you give to our questions will be treated in **the strictest confidence**. No-one outside the research team will have access to any of your personal details, and the study's findings will be presented in such a way that **no individuals or organisations will be identifiable**. The study will not have an impact on the level of care given to your loved one.

If you have any questions about this interview please do not hesitate to contact me on xxx xxxxxxx or by email at m.k.w.abhayasinghe@keele.ac.uk.

Once again, many thanks for your participation thus far.

Yours sincerely,

Kalpani Abhayasinghe
Researcher

Appendix 08: Information leaflet

Institute for Research & Development

Keele University

The Study on Dementia Care-givers in Sri Lanka

Information for Participants

Thank you for your participation in the 10/66 Dementia Prevalence study. We would like to invite you to take part in an interview in order to understand your views and experience of caregiving for your loved one with dementia. Before you decide to take part, it is important for you to understand what this research is about and what it will involve.

This information leaflet describes what will happen in the interview should you decide to take part. Please take time to read this carefully. You can discuss it with others if you wish.

Thank you for reading this leaflet and considering taking part.

What is the purpose of the study?

The interviews are part of a research study nested within the 10/66 dementia prevalence study that you have been taking part in. We want to know your views and experience about the caregiving for your loved one with dementia and find out how you manage with the caregiving role.

This will help us to explore the aspects of dementia care in order to help for families and patients with dementia in the future.

Why have I been invited?

You have been invited to take part in an interview because you are a family member and/ or providing care for a person with dementia over period of time.

Do I have to take part?

No, you can choose whether or not to be interviewed. **The healthcare of you or your loved one will not be affected in any way**, whether or not you decide to take part.

You can decide whether to take part in individual interview or group interview or both. You can choose not to answer any question you are not comfortable with. The interview will be audio-recorded. If for any reason you feel uncomfortable during the interview the recorder will be stopped. Any part of the recording that you do not wish to be used in the research will be deleted.

What do I have to do, and how long will it take?

If you agree to take part, the interview will be with a researcher and will last about 60 to 90 minutes. It will take place at a time and place to suit you.

During the interview the researcher will ask you questions about your experiences of caregiving, your views on caregiving and dementia care services.

We also want to find out how your caregiving role affects with your life and what challenges you face them Individually or as a family. You may be interviewed alone or along with the rest of the family.

We just want to hear about your views and experiences, so there are no right or wrong answers. You do not need to do anything to prepare for the interview.

Following the interview, the recording will be typed out to make a paper copy of the interview - called a transcript. All of this will be explained to you again at the beginning of the interview, and you will be asked to sign a consent form.

Will my taking part in this study be kept confidential?

Your personal information will be treated in the strictest confidence. Each person who takes part in an interview will be given a study number so that their personal details remain confidential. The paper transcript from the interview will be anonymized, which means it will not contain any information that would identify you, for example your name or address. If you mention the names of people or places, these will be removed from the paper transcript.

This anonymized information will be kept and may be used in other research studies conducted on dementia by Keele University or IRD (Eg: Dementia Research in collaboration with 10-66 dementia group), but researchers who work with this data will not have access to your personal information.

Quotations from your transcript may be used in reports but it will not be possible for people to identify you.

The original audio recordings, non-anonymized information and all anonymized transcripts will be stored securely within IRD until 5 years after the completion of the study (Up to 2024). After this time it will be destroyed.

What might the risks be of taking part?

We do not anticipate there will be any risks to you in taking part, and you will be under no pressure to reveal any information that you are not comfortable with.

What are the possible benefits of taking part?

Taking part in an interview will not have any direct benefits to you in terms of your loved one's health; however, some people find talking about their health experiences to a researcher to be a positive experience. You will also be contributing to a study that we hope will help people with dementia in the future.

What should I do now if I want to take part?

You do not need to do anything now; Kalpani Abhayasinghe, the principal researcher will contact you shortly by telephone to answer any questions that you may have about the interview and to ask you if you would like to take part. If you say that you would like to take part, you and Kalpani will arrange a convenient date and time. Once a convenient date and time has been arranged, a confirmation letter will be sent to you.

What will happen if I said Yes to take part but then change my mind?

You can withdraw from taking part in an individual interview before or during the interview and up to one month after the interview date without giving reason, by telephoning Kalpani on xxxxxxxxxx.

Data cannot be withdrawn from the study after that date, but you may still ask for your quotes not to be included in the write-up.

If you wish to withdraw from group interviews it is also possible up to one month. However, it is not possible to remove your contributions from the transcript, because others may be directly responding to things you say and the data would make less sense if we removed this information.
However we can assure that what you say won't be quoted directly in any output if you choose to withdraw from the group interview.

What will happen to the results of the research study?

Researchers will publish the results in research conferences and academic journals.

Who is funding and organising the research?

This study is funded by the Research Institute for Primary Care and Health Sciences, Keele University, UK. The Institute for Research and Development (IRD) Sri Lanka is facilitating the principal researcher during the data collection process.

Who has reviewed the study?

To protect your interests, this study has been obtained ethical clearance from an independent group of people, called a Research Ethics Committee (ERC) from Keele University UK, and also Kotelawala Defence University (KDU) — Sri Lanka.

Who can I talk to if I have any questions?

If you have any questions, or would like further information about this study, please contact, Kalpani Abhayasinghe, Researcher on xxxxxxxxxx.

What if I need to speak to someone outside of the study team about this study?

If you have any general questions or concerns about taking part in research, you can contact The Institute for Research and Development (IRD).

Telephone:

+ 94 11 2863084
+ 94 11 5662895

website link:
http://www.ird.lk

Thank you for taking time to read this information.

Appendix 09: Informed Consent form

The study on Dementia Caregivers in Sri Lanka
Consent Form for Interviews

Study ID Number

Researcher: Ms. Kalpani Abhayasinghe

REC Number: xxxxxxx

Please initial the box if you agree with the statement

1. I confirm that I have read and understand the information leaflet (Version 1.0: 10.09.2016) for the above study…… ☐

2. I have had the opportunity to ask questions and have received satisfactory answers where needed..... ☐

3. I understand that can withdraw from the study before or during the interview and up to one month after my interview date …… ☐

4. I understand that my participation is voluntary, that I can refuse to answer a question, or withdraw as mentioned above, without giving any reason, and without my legal rights being affected……..……..... ☐

5. I understand that the interview will be audio recorded and that will be stored in an encrypted device with an anonymous file name up to 05 years after the completion of the study, and after this time it will be destroyed …….. ☐

6. I understand that the recording will be transcribed, and that the original transcript will be stored in a secure location within IRD, and kept for up to 05 years after the completion of the study, and after this time it will be destroyed.. ☐

7. I understand that the anonymised version of the transcript will be kept and may be used in other research studies, but researchers who work with the data will not have access to my personal information…….. ☐

8. I would*/ would not* like a summary of interview results to be sent to me..... ☐

9. I agree to take part in the interview..... ☐

*delete as appropriate

Please sign and date on the line below:

Name of Participant (Please Print)	Date	Signature
Name of Researcher (Please Print)	Date	Signature

Thank you for your help with this research study.

Appendix 10: Informed Assent form for children

Institute for Research & Development

Keele University

The study on Dementia Caregivers in Sri Lanka
Consent Form for Minors

Study ID Number

Researcher: Ms. Kalpani Abhayasinghe

REC Number: xxxxxxx

Please read and fill in this consent form (circling Yes or No), initial and sign below.

			Initials
1. I have read and understood the information leaflet (Version 1.1; dated 24.10.2016) for the above study) OR have had the study explained to me by my parent/guardian.	Yes	No	☐
2. I have asked any questions I wanted to about the study.	Yes	No	☐
3. I understand that it's OK to stop taking part in the study before or during the interview and up to one month after my interview date and this won't change the care that my loved one receive.	Yes	No	☐
4. I understand that my participation is not compulsory and I can refuse to answer any question.	Yes	No	☐
5. I agree to my interview being audio recorded and being reviewed by an authorised person from the research team.	Yes	No	☐

I agree to take part in the above study *('Yes' response to items 1-5)*	**Yes**	**No**	☐

PARTICIPANT age less than 18 years (assent):

Signature/mark: _____

Name: (please print) **First name:** _____ **Last name:** _____

Today's date (DD/MM/YYYY): ☐☐ / ☐☐ / 2017

1.	I understand that the audio recording will be transcribed, and the original transcript will be stored in a secure location within IRD, and kept for up to 5 years after the completion of the study, and after this time it will be destroyed	Yes	No	☐
2.	I understand that the anonymised version of the transcript will be kept and may be used in other research studies, but researchers who work with the data will not have access to my child's personal information	Yes	No	☐
3.	I have checked with the child and he/she understands the information leaflet and the information mentioned in this assent form	Yes	No	☐
4.	I consent voluntarily for my child to participate in this study	Yes	No	☐

PARENT / GUARDIAN CONSENT:

Signature: _____

Name: (please print) **First name:** _____ **Last name:** _____

Today's date (DD/MM/YYYY): ☐☐ / ☐☐ / 2017

RESEARCHER:

Signature: _____

Name: (please print) **First name:** _____ **Last name:** _____

Today's date (DD/MM/YYYY): ☐☐ / ☐☐ / 2017

Thank you for your help with this research study.

Appendix 11: Informed consent (by Proxy) for the PwD

The study on Dementia Caregivers in Sri Lanka
Consent Form on behalf of Person with Dementia

Study ID Number

Researcher: Ms. Kalpani Abhayasinghe

REC Number: xxxxxxx

Please initial the box if you agree with the statement

1. I confirm that I have read and understand the information leaflet (Version 1.1: 24.09.2016) for the above study…… ☐
2. I have had the opportunity to ask questions and have received satisfactory answers where needed..... ☐
3. I understand that my loved one can withdraw from the study before or during the interview and up to one month after my interview date ……..… ☐
4. I understand that my loved one's participation is voluntary, that I can refuse to answer a question, or withdraw as mentioned above, without giving any reason, and without my legal rights being affected…….……..... ☐
5. I understand that the interview will be audio recorded and that will be stored in an encrypted device with an anonymous file name up to 05 years after the completion of the study, and after this time it will be destroyed …….. ☐
6. I understand that the recording will be transcribed, and that the original transcript will be stored in a secure location within IRD, and kept for up to 05 years after the completion of the study, and after this time it will be destroyed.. ☐
7. I understand that the anonymised version of the transcript will be kept and may be used in other research studies, but researchers who work with the data will not have access to my loved one's personal information…….. ☐
8. I would*/ would not* like a summary of interview results to be sent to me..... ☐
9. I consent voluntarily for my loved one to participate as a participant in this study ..... ☐

*delete as appropriate

Please sign and date on the line below:

Patient's name: _____

Relationship to the patient: _____

Name of main caregiver/ legal guardian (Please Print)	Date	Signature

Name of Researcher (Please Print)	Date	Signature

Thank you for your help with this research study.

Appendix 12: The confirmation letter

Mrs xxxxxxxxxxxxx

Address

Our ref: xxx
[Date xxxxxxx]

Dear xxxxxxxxxx

Thank you for agreeing to take part in an interview in this dementia research.

This is to confirm the details of the interview which will take place on: **[date and time]**

The interview will take place at **[venue].** During the interview you will be asked about your experiences of caregiving, your views on caregiving and dementia care services. The interview will last approximately 60 to 90 minutes.

I would like to thank you again for agreeing to take part in an interview. If you have any queries, please do not hesitate to contact me on xxx xxxxxxx.

Yours sincerely,

[signature]

Ms. Kalpani Abhayasinghe

Researcher

Appendix 13: The Zarit caregiver burden interview

0: NEVER
1: RARELY
2: SOMETIMES
3: QUITE FREQUENTLY
4: NEARLY ALWAYS

Participant ID:

Please circle the response the best describes how you feel.

Question		Score				
1	Do you feel that your relative asks for more help than he/she needs?	0	1	2	3	4
2	Do you feel that because of the time you spend with your relative that you don't have enough time for yourself?	0	1	2	3	4
3	Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?	0	1	2	3	4
4	Do you feel embarrassed over your relative's behaviour?	0	1	2	3	4
5	Do you feel angry when you are around your relative?	0	1	2	3	4
6	Do you feel that your relative currently affects our relationships with other family members or friends in a negative way?	0	1	2	3	4
7	Are you afraid what the future holds for your relative?	0	1	2	3	4
8	Do you feel your relative is dependent on you?	0	1	2	3	4
9	Do you feel strained when you are around your relative?	0	1	2	3	4
10	Do you feel your health has suffered because of your involvement with your relative?	0	1	2	3	4
11	Do you feel that you don't have as much privacy as you would like because of your relative?	0	1	2	3	4
12	Do you feel that your social life has suffered because you are caring for your relative?	0	1	2	3	4
13	Do you feel uncomfortable about having friends over because of your relative?	0	1	2	3	4
14	Do you feel that your relative seems to expect you to take care of him/her as if you were the only one he/she could depend on?	0	1	2	3	4
15	Do you feel that you don't have enough money to take care of your relative in addition to the rest of your expenses?	0	1	2	3	4
16	Do you feel that you will be unable to take care of your relative much longer?	0	1	2	3	4
17	Do you feel you have lost control of your life since your relative's illness?	0	1	2	3	4
18	Do you wish you could leave the care of your relative to someone else?	0	1	2	3	4
19	Do you feel uncertain about what to do about your relative?	0	1	2	3	4
20	Do you feel you should be doing more for your relative?	0	1	2	3	4

21	Do you feel you could do a better job in caring for your relative?	0	1	2	3	4
22	Overall, how burdened do you feel in caring for your relative?	0	1	2	3	4

Interpretation of Score:

0 - 21 little or no burden
21 - 40 mild to moderate burden
41 - 60 moderate to severe burden
61 - 88 severe burden

Appendix 14-A: An example of an analysed transcript (A Group Interview)

REC No: 170614_GI_01

Participants: Mrs. Rani (Main Caregiver), Mr. Kithsiri (Main Caregiver's Husband), Her Son, The PwD, Interviewer (KA)

Date Interviewed: 14/06/2017

Venue: Participant's home

Time: One hour 15 minutes

Transcribing time: 9 hours in Sinhala

Translating time: 4.30 hours

Themes/ sub-themes	Transcription	Interpretations/ Condensed meaning units
Support – no direct involvement of other family members **Challenges-** **Lack of awareness of dementia** **Illness perception – A mental illness**	**Interviewer: To begin, I'd like to get some basic information about you. Tell me about yourself and family?** **Main Caregiver:** Myself..., husband and two children are at my home. My husband is not at home often, he's a tour guide. So does my Son. After completing his A/Ls [in 2011] he now studies a hotel management course in Hotel 'G'. Daughter is working too; she is mostly at home only during night time. In near future, father and I are going to be alone at home…. He has 4 daughters and 2 sons. **Interviewer: So, how did you first get to know that father has this illness?** **Main Caregiver:** Not that long, It's about 2 years since he got this… He had it... At first we had no idea what kind of illness this was.. He had certain changes in his behaviour… Now we take medicine from Prof. ASD, from the Hospital 'A' [Private sector]. My elder sister has some idea about the illness, she often goes to hospital. She has arthritis, her husband also developed a similar disease due to nerve death... He was a heavy drinker, a seaman... So, sister had some knowledge about this illness. It's my elder sister who first suggested 'Thaththa [father] might have this type of illness [mental illness], Let's see a doctor.' **Interviewer: How did you first learned this condition is exactly dementia?** **Main Caregiver:** It's just…He started doing things that he hadn't done before... **Interviewer**: What type of things?	Even though the family consist of many siblings, only **one daughter has volunteered** to look after father. Children all grown up, no much family burden to caregiver. Had no idea at first Previous experience of a similar condition lead to seek medical advice/ a famly member recognised initial symptoms Firstline treatments – westernised medical model How family members first noticed behavioural changes PwD's behaviour/ personality before diagnosis

Illness perception – He lies (Denial) **Sense of Burden before the diagnosis of illness** **Challenges of Caregiving –** **- Wandering behaviour** **- Stigma by wider society** **Service needs – increase awareness among wider society (e.g. Police)** **Meaning of Caregiving_Control**	**Main Caregiver:** It's just this… didn't like his Son-in –Laws. Looking for their faults all the time... Ill-treated... Didn't like his daughter-in –Laws... Things like that, you know. **Interviewer: Aa... haa... Has he had any forgetfulness?** **Main Caregiver:** Yes. But it's much worse now. But even now there are occasions that they [husband and family] say he lies and pretends... [chuckles] Sometimes he has a very good memory... on and off... Can remember things that we cannot even recall… Lately... no one wanted to keep him, he was a trouble... Then what I did, I agreed to take the responsibility to take care of him... **Interviewer: What does that mean? No one wanted him?** **Main Caregiver:** [nodding to say yes] No one liked him... He was a trouble... Because, most of the time they were not home... And father was running away from where ever he lives... Twise we found him at Police stations... When others left home in mornings, father wanders around the roads... I think he tends to forget and go somewhere else... Once he has gone to PPP [A town about 25 km away from home]. And the police called my elder brother who lives in GGG [A town about 110 km away from home], as it was the address written in father's identity card... Brother was blamed by the police... saying 'is this the way you look after him..?' That time my brother collected him from the police station. **Interviewer: Hmm…** **Main Caregiver:** Can't keep him any of our homes, he runs away... Now, I **keep him under lock and key** [smile]... Now… Yesterday, He was trying to escape... I was in the bathroom,	Perception of others - Family members do not believe he has forgetfulness Volunteered to become the caregiver (No much choise left for her) Wandering behaviour was not recognised by the family members Wandering and impact on family as a whole, stress, seen as trouble (not as part of dementia) However, the MC justifies/ acknowledges the forgetfulness Police blamed Son, without proper understanding of dementia - Stigma Use force to control considering safety of the PwD/ fear of loosing Caregiver explained the alterations they made to their house in order to facilitate caregiving

Sense of Burden -suffering **Challenges of caregiving** **Care Model – bio-medical** **Social Awareness – Neighbours**	washing a carpet. early in the morning. Both my husband and son were still on bed in upstairs... It was just dawn. When I look, He has gone… **Interviewer: Means? He has gone out from the gate?** **Main Caregiver:** Yeah! It was not locked... If it's not locked, he opened the gate, and left... Knows well whether we are alert of him or not... if [we are] not; he escapes. [smiles]... At times he opens the back gate and escapes... That's the jungle on that side. It's been a long time that we suffer because of thaththa... Now only we have a lockable gate… Shouting at the neighborhood people who are nearest. But now he's not that sick after taking drugs from the hospital. **Interviewer: Means? Was his shouting got less with medicine?** **Main Caregiver:** Yeah... It got reduced with medicine... It was not possible to control him in the past. He used to walk around the house with a bag full of clothes... Telling people things like 'I am kept here by force; I was not given anything to eat. get me out of here...' things like that. **Interviewer: hmm… Do you mean he's lying?** **Main Caregiver:** lies... lies… **Interviewer: So, what do you do in such occasions?** **Main Caregiver:** The neighbours know it… They're not gonna see him, they avoid father... [to avoid agitating him/ in a good way] People know him well, they have seen him when he was in good condition... They are so sorry for what happened to father...	Could manage behaviour/ symptoms with medication - Trust on the western medicine Lack of support from the PwD Neighbours know the condition (Less stigma) sympathy Wider community is aware of PwD's condition [that he has a mental illness] – support the family in caregiving process Negative Illness perceptions Lack of understanding & awareness leads to threat and abuse of the PwD. It creates conflicts/ differences in the way in which care is given

Abuse/ Threatening -Sending away from home as a punishment **Challenges of Caregiving – running away** **Rejecting the PwD due to sense of Burden/ misunderstandings of BPSD** **Support from extended family and the community**	**Interviewer: Tell me more about your family.** **Main Caregiver:** I have two elder sisters, one younger sister and two elder brothers. My eldest brother is strict... He does not tolerate father's nuisance. What he does is, locking father inside the house, threat him. **Interviewer: Threat him saying what?** **Main Caregiver:** saying that he will send him to an elderly home... **Interviewer: was your father with your brother before he comes to you?** **Main Caregiver:** No. he wasn't living in one place... Maximum two days in one place… No one knows, he runs away... There are no walls [barriers/ gates] in those houses, now anyway they can't keep him. **Interviewer: Has he being with your other siblings even after diagnosed to have dementia?** **Main Caregiver:** He had been in several places... But, no one is willing to keep him with them lately… **Interviewer: How long he's living here [permanently]?** **Main Caregiver:** Since 2 months he lives at my place… My brother lives in TTT [nearby town to main caregiver's place]. When he insists that he needs to go, I call a three-wheeler and send him to my brother's place. But, he runs away when he is at brother's place. It's when was running away from his place, he got caught by the police once... Sister-in-law is afraid	Before diagnosis - Rejection from other family members/ relatives **Resistance** to caregiving role Sharing the load of looking after person with dementia Differences in caregiving styles/ attribution of caregiving role/ coping among different family members – control/ afraid -Some support from another sibling -Others Cannot control his behaviour Not a long time being the main caregiver

Control – lack of control **Lack of awareness** Sense of burden and stigma/ Shame **Concerns of PWD as a person**	of dad... So she allows him to do whatever he wants when my brother is not around... If father knows he can surrender someone he behaves aggressively. **Interviewer: Then, for how long you have been the main caregiver?** **Main Caregiver:** I'm the one who **looking after him for 2 months now**... Even before he comes and goes to our place… Says he can't stay long... We didn't know the severity of his condition... so we let him go when he say he wants to go... Meantimem, there were big issues... like… He took his clothes to nearby shops and tried to sell them... Told that and this [inappropriate comments] to others... (Reflection: She sounded embarresed. Her son was laughing as if he found these incidents very amusing.) **Interviewer: Means? The ones he wears?** **Main Caregiver:** Yeah… his clothes. He's known by all the shopkeepers up to junction... **Interviewer: How he sell those?/ What does he tell to sell them?** **Main Caregiver:** Tells he sell them as 'he hasn't got cash...' He loves buying lotteries... [pause...] Smokes a lot… but now not much... **Interviewer: Does he get alcohol too?** **Main Caregiver:** Not always... he takes a small drink like in a party. But he's not addicted... But smokes a lot so often… Now, he smokes if only I give him... Sometimes he even forgets that… **Interviewer: Does he ask for cigarettes? How many cigarettes per day?**	Concerns of the PwD as a person/ Emotional needs. It appeared that Rani was concerned about her father's emotional needs and facilitated them to some extent (e.g. allow smoking) **Dependency of the PwD** Allow the PwD to be happy/ free will (Respecting his needs as a person???) Misunderstanding of forgetfulness/PwD's behaviour by the family members as a deliberate act?

Respect for PwD's will **Illness Perception – He denies/ Lies**	**Main Caregiver:** Yes. He asks. Dr. ASD asked to 'give him, if he asked for... why would you control now? ' If we give him he would smoke even 10... Now, he can't remember, ask only if he recalls. In fact, he doesn't ask from me, asks [for ciggarrets] from either my son or husband... **Husband:** He asks from *'body acting!'* Haah haa! [He was acting how] So we give him... [Reflection: The person with dementia came to living room and sat on the sofa. He was not interested to talk, but was smiling at me. He was wearing a towel around his neck] **Main Caregiver:** He can hear well… see well... well alert of what we say about him... But denies whatever he does... **Interviewer: Is it because forgetfulness? Or…** **Main Caregiver:** No… if he does something wrong... [like urinating outside the toilet...] **Interviewer: Aahh.** **Main Caregiver:** We give him a torch to keep with him during night time... He likes torches very much, and hides them... We couldn't find one them yet… **Interviewer: Does that mean… he hides them because he likes them?** **Main Caregiver:** Yes. He requests it to keep with him. He needs it to go to toilet when we switch off the lights [at night]. Once we give that, he hides them somewhere and no one can find'em again… [Reflection: The PwD was wearing a sarong, with a belt around his weist... Around that belt there were more than three racers, a comb and a torch, hanging. He was wearing a towel	Full-time Engagement in Caregiving She has lost time for herself due to absconding risk and vigilance Illness perception: Family member's perception towards illness/ PwD's behaviour- Perception of PWD being fed up about being stuck in one place Family view of PwD's current life and his past (comparison - now & then) -seems to understand the PwD's emotional state/

	as a scarf around his neck. In his shirt pocket there were more than three boxes of matches... I noticed he was touching them time to time, as if to make sure that they are safe.]	justify reasons rather than blaming the PwD
Engagement in Care **Sense of Burden -Vigilance**	**Interviewer: How many hours per day you care for your father? How do you feel?** **Main Caregiver:** Whole day I'm with him. Need to be alert all the time. Usually, I take a nap during day time... If son is not at home, now I go to sleep only after locking [the gate, doors] from everywhere. **Interviewer: Do you lock all the doors, windows and gate?** **Main Caregiver:** Lock everything... We have no grills for windows, he creeps through the windows... Now we have to pay more attention, so very vigilant even for small sound.	Taxi drivers misused the PwD/ stealing money by cheating – social values/ taking advantage of the forgetfulness of PwD Seems lack of support from community is a challenge for caregiving and safety of the PwD. -Losing money/ phones -taxi drivers steal money/ phones -justice???/ trust???
feeling of Dependency/ Lack of Autonomy/ status Dependency **Sense of lacking PwD's identity**	**Husband:** Not all the times... Only at times... he tries to escape. I think he's fed up being at one place. He used to travel a lot early days to see his children... Used to visit us, her sister in Colombo... Chuh! Now he's upset not being able to do so... **Main Caregiver:** Yeah… He sometimes talks to Kithsiri [her husband]... 'Who I was? How much money I was handling..?' Aaaah! Money... Father used to lose his money a lot… That's how we first got to know about illness... We have no idea what happened to 50,000 rupees [which he lost one time]. **Interviewer: Aah! That means before you came to know his illness he was free to live his own life. Go anywhere. Spend as he wishes?**	Some taxi drivers supported the family to find the PwD/ even bring him home when they found him wandering at road

Service Needs - Awareness of Legal/ Ethical/ Moral aspects of dementia care **Support – Taxi drivers**	**Main Caregiver:** Yes. He had money... My younger sister also sent 10,000 rupees per month, usually 5000 rupee notes... He had spent those on three wheelers, as he gets lost, forgets the way home… **Husband:** Why phones? Ha haa! [laugh] **Main Caregiver:** He lost two phones... When he gives the phone to three-wheel driver, to ask the way home from someone in the contact list; they take the phone away with them... He was at my place in both the times he lost those phones... Runs away from home, goes to Korathota [the junction nearby home] and get a three wheeler... Onetime… a driver has taken 2000 rupees and his phone to go to [a nearby town] from our place [ideally it costs less than 500 rupees] **Interviewer: Means, was he cheated by driver?** **Main Caregiver:** Yes... Even to date that phone rings... Isn't it son? One sim works even now, seen in IMO... but we didn't ask... no use… **Husband:** Now, wherever he goes... Still he can remember the address so comes back to our place.. Three wheel drivers also know him, so they bring him home... to GGG [name of the housing scheme they live] **Main Caregiver:** He knows the way home from KD [nearby town]. Can remember this place… **Husband:** He has forgotten all others… One of his daughters lives at [a town]... He can't go there... A sister lives at [another nearby town], can't go there either... But goes to GGG by	Bus conductor takes the responsibility of the PwD while he's travelling to home town PwD is deteriorating gradually, and other family members reject him - The need to keep PWD away from potential trouble/danger PwD's behaviour was not acceptable -it leads to caregiver burden - lack of care - Rejection due to behaviour Why other sisters do not want father to be with him ? -Need for constant vigilance -Psychological/ Emotional challenges of care -No permission from their husbands -shame and stigma Love Vs Caregiver Burden (perception from family that if father does get out and about that it shows signs that they don't love him?)

Support – bus conductor **Challenges** **Conflicts** **Negligence / Rejection** **Shame and Stigma** **Sense of burden**	bus via highway... from there to home [his village]. When we send him home, we hand him over to the conductor, bus doesn't stop on the way know… **Main Caregiver:** But, now we don't send him... Last time father faced lot of troubles when he was at Galle... Now I'll keep him forever... Now we don't send him there anymore. **Interviewer: That means?** [long silence] [Reflection: The main caregiver was hesitating to answer. Perhaps she still lacks the trust/ rapport to reveal family matters or she doesn't want to betray her siblings infront of her husband.] **Main Caregiver:** At last... father had nowhere to go... every one rejected him, because trouble was too much to bare… Such shame... even though he's our father, what he did was shameful at times... Now, in this area people [neighbours] know about father... but where my younger sister lives [hometown] she is with her in-laws, so it's a shame for her to keep him with her.. In fact, when he goes there does weirder things [like wear unusual clothes, wander in roads, taking mud baths]. He behaves shamefully in village. **Interviewer: Ah haa..!** **Main Caregiver:** Now, there's another sister lives in Waththala, Enderamulla. But her daughter sits for A/Ls this year. She can't leave him at her house. When he's left alone he goes to nearby houses... now other sister also cannot take the responsibility as she lives with her daughter who got two kids.. Like that, there were circumstances that he had nowhere to go… It's not that they don't love him anymore… No one can control him...	Skepticism about the illness Volunteering to become a caregiver Main challenge is PwD's wandering behaviour Repetitive questioning make the caregiver irritable Caregiving responsibility and issues of maintaining personal hygiene/ disruption to housekeeping Use Force to control -PwD's Autonomy Vs Dependency -intention to help vs Control

Guilt **Engagement** **-Commitment to care** **Awareness** **Anger towards PwD** **Challenges of Caregiving** **-wandering behaviour** **-repeatedly asking the same thing** **Engagement – Vigilance**	When he disappears from home, everyone gets worried, looking for him... They want father to learn a lesson, so let him do whatever he wants... But when he goes missing every one of us feels bad... [sigh] Finally, I volunteered to keep him at this place... Now he's on medication, but doctors told three's no permanent cure. **Husband:** No much trouble from him... huh! [Reflection: I felt ironically, he said the other way, he sounded a little angry about his father-in-law's behaviour] **Main Caregiver:** Only trouble is, we can't keep him in one place. His only intention is to go out… for breakfast he takes either bread or string hoppers... After that, only intention is to go out… **Interviewer: Can you tell me, how you spend the day as his main caregiver?** **Main Caregiver:** dad is awake by 5 am. We get up around 6am… Till then he lies on the bed. I give him his tea… then repeatedly asking 'can I take a shower? Can I? Can I?? ' No matter how much I say no, he keeps asking the same… **Interviewer: means, is he repeatedly asking the same thing?** **Main Caregiver:** Repeatedly asking the same thing.. He only get satisfied when I say yes... When he goes to shower, he takes fresh clothes, but he returns wearing the same dirty cloths he was wearing, or keep the used ones in the cupboard... I'm vigilant on those, otherwise it gives a bad smell on other fresh cloths in the cupboard...	Let him do household chores with caution Give Medication to fall asleep during day time – force to sleep (decision making by psychiatrist and caregiver) – Against the best interest of the PwD MC appreciated PwD's good qualities Caregiver take decision about PwD's medication against medical advise - side effects? - Risk of falls - lack of awareness - overdose of medication as a remedy to wandering behaviour

Control Autonomy of the PwD? **Autonomy** **Control – force to sleep**	**Interviewer: Who wash his clothes?** **Main Caregiver:** He himself does that… But, I shout at him and do it myself forcefully.. Otherwise, he can't do it well. Then, after shower he sweep the house and verandah, sweep the compound also using the same broom... **Interviewer: Do you allow him to do that?** **Main Caregiver:** Yes. Doctor asked, let him do those... But, he pretend to sweep the yard and silently runs away from the gate… **Interviewer: what about the time when this happens?** **Main Caregiver:** Still about 10am… He takes breakfast around 7 – 7.30, then I used to give him pills [medication] so he feels sleepy. He is nodding sometimes... But does not go to bed, saying he falls asleep if he goes to bed... He doesn't like sleeping at all… **Interviewer: Does he sleep if someone is nearby?** **Main Caregiver:** No It's not... When I ask him to go to bed… he says 'I'll fall asleep then...' He doesn't like to sleep at all if someone is nearby... It's his nature even before... He used to sleep alone. He doesn't eat his meal if someone touches the food... or share... He very much likes if someone arrives, likes to give away food and treat others… He was like that even when we were kids... It's a habit. **Interviewer: Then?**	lack of trust on efficacy of drugs perception of caregiver – 'medication is painful for the PwD' PwD has poor insight Hallucinations & Delusions? Seems the MC still has no clear idea about the nature of dementia (regarding incontinence) Caregiver's Understanding and Justification of the behaviour of PwD positively – (Perception of enduring personality construct despite dementia)

Guilt **Mental capacity of the PwD Vs decision making for best interest of the patient** - To ease the caregiving/ management **Knowledge about medication**	Main Caregiver: It's about 1pm when we have lunch.. If I gave him one more tablet he sleeps about one more hour… But I don't give it now.. I feel sad to look at his face, he nearly falls like a drug addict… [Reflection: She has given overdose of sleeping tablets to make him sleep earlier; it's when she attended clinic the MO advised her not to and changed the current medication. I remember that day at clinic; she was pleading the doctor to do something to make him sleep, as she cannot keep him at home during day time inside the home] **Interviewer: Is there any improvement from the medication you obtained from clinic?** **Main Caregiver:** New **medication from clinic is much better than what Dr. ASD gave**... The morning dose of Quetiapine [3/4th of the tablet] makes him sleepy... He can sleep around one hour... But he doesn't sleep comfortably... lies in a corner of his bed. My son always tells him to lie in the middle, but he never does... Always he's very suspicious... I think he's afraid that someone may kill him... [talks about PwD's delusions and hallucinations] That's why he doesn't sleep. **Interviewer: For how long he tells that?** **Main Caregiver:** He does not say so always. But if someone chats [with him] too long, he says these. I now realise that he does not sleep because of his fear... He is suspicious that someone will kill him...	Hallucinations and delusions?? – symptoms of dementia symptoms of dementia - Hallucinations/ Delusions Rani knew they were his thoughts, but could not relate the symptoms as BPSD PwD's agitation and behaviour changes during family events have become a burden Lack of awareness - signs and symptoms of the

PwD's Illness Perceptions – He denies **Attribution of symptoms**	**Main Caregiver:** Recently he got a stomachache... and he told me, 'Your son has poisoned me..! I know who did this…' He is ashamed to acknowledge this is an illness... He wants to blame someone else, like we are responsible for this. Now, yesterday morning... He has passed water (urinated) in front of the door to bathroom… **Interviewer: Did you ask why?** Main Caregiver: yes I did... He denies… **Interviewer: Do you think he does that deliberately? Or?** **Main Caregiver:** Oh, No... either he is so sleepy, or he's out of consciousness... If not, he never does so, openly. That's not him... He is shy… **Interviewer: How do you spend the evening?** Main Caregiver: Evening he stays by himself… Kids in the housing scheme play in the road towards evening... So he watches that. Dad love kids. He even gives sweets [tofees] to them… It is in the mornings he troubles me a lot... There's no trouble towards evening… Now not even during the night... Around 7 – 7.30, he goes to bed after dinner... Bt does not sleep. Lying on the corner of his bed he watches us going here and there… Then… tells 'a family goes upstairs... two couples goes upstairs..!' [Reflection: May be hallucinations, even when I was talking to him I noticed his attention was with something else time to time. I could have probe them more from the PwD, but I didn't as it was clear from the caregiver's statement.]	illness/ about PwDs fear of being among the crowd Support from brother to control father's behaviour in difficult situations (Sharing responsibility for caregiving when symptoms are high or unmanageable) Coping - management of situation, passive approach PwD is passed around the family, suggests a need for some respite I do it willingly It's merit Duty/ responsibility/ I am the only one Caregiver's thoughts, personal values, religious beliefs and assumptions (cognitions) leads to her caregiving activities (behaviour) and her perceptions/ emotions (for example guilt) – [cognitive Model of Care?]

Challenges of Caregiving	**Interviewer: Is it Real? What do you think? Is it because of the illness??** **Main Caregiver:** It's his thinking. Sometimes he tells us, 'my sisters are cooking in the upstairs!' Now that brother he told you about… he passed away sometime back… [Reflection: Before I begin the interview the PwD was talking to me, and I remember he told me about this brother]. Sometimes tells, 'they are talking to me..' In some nights, rarely, he has nightmares... when I go near and ask... he tells 'my mother/ sister talked to me..' **Interviewer: Does he show them to you? Like they are right here?** **Main Caregiver:** No, he does not… **Interviewer: Have you observed, his attention changes when he's talking with someone?** **Main Caregiver:** No... But, if someone walks near when he's talking with me... He shows them by eyes... but, he does not point/show invisible things... He gets restless when in crowded places… much afraid of strangers... Such times, he does not stay at home, and demands to leave home... Now, next door had an almsgiving, that day we couldn't keep him at home at all... He was insisting to leave, much restless after seeing the crowd next door... Don't know why, he behaves like frightened in such situations. **Interviewer: What do you do in such situations?** **Main Caregiver:** I send him to my brother's home... They also keep him only for maximum of two days. They can't control him. My brother goes to work, his wife can't control my dad. They send him back to me in a three wheeler. I can somewhat control him [the way he	recognition of dementia as the causal factor Support from the family members are at various levels. Some do support but with anger. Inconsistancy of forgetfulness confuses the family members which also lead them to think PwD lies/ cheats
Challenges of Caregiving – sense of burden related to PwD's agitation		
Meaning of Caregiving - Control		

Guilt **Meaning of Caregiving** **Sense of burden** **Meaning of Caregiving -Connectedness -Sense of Belongingness**	behaves when aggressive] My son is also there, he too can control. He does not so hard on me... I too don't care. When he tries to escape [through the gate], I do not care... I use to do my own work without paying attention to him… Mostly he is disturbed a lot in mornings… around 11 to 12 only. Towards evening he's calm, no trouble at all... **Interviewer: Is there any occasion that you feel burdened when you provide care for father?** Main Caregiver: No... I am willingly looking after him. Where else can I get such a merit like treating your parents? Isn't it? What's the use of us going to temple or church if father stray/wander around roads? Infact, I am the only one who is free to treat him, I am at home most of the times… But still, there are situations that **I feel to give up, when he troubles too** much... [Reflection: She said those with a smile in her face. She looked down when she said 'I feel to give up'. Her voice was low. I felt like she has an internal conflict of doing good and bad for her father. However, she is proud that she looks after him, same way she feels guilty when she has to blame him] **Interviewer: What do you do in such situations?** **Main Caregiver:** I use to think, 'whatever it is he's my father...' [Reflection: Perhaps it is her coping mechanism to think of the role and duty] **Interviewer: Are there occasions that you cry?**	Safety concerns -Fear of getting injured -Uncertainty Concern of spending time with the PwD/ make him happy Repeated questions -irritability

Meaning of caregiving - **Gratitude**- Giving back **willingness**- I like to care **Support** **Illness perception – -It is not due to illness -deliberate act**	**Main Caregiver:** I'm not a person who cry usually.. So **I think, 'Father was not someone who treated us badly...** All his current behaviour are because of his illness...' I am very much like to care for him... (Reflection: potentially a reflection on the role of duty, a weighing up of the contribution of father in the time up to the dementia, this has been shown in other research where previous relationship quality is a determinant of quality of caregiving) **Interviewer: How about others in your family?** **Main Caregiver:** My son helps me a lot. So does him [husband] most of the times... It's true he gets angry... but only for that moment... [slow voice] he gets angry for what father does, He thinks father deliberately behaves as such, having good consciousness... and memory... Now, last week, there was an opening of a shop. He [husband] gave me money to participate that occasion... He also gave father a 20 rupees note, while he was lingering around... Usually we don't give him money now. If someone tries to give, I say no... why, he leaves house if he has got money in his hand. So since morning, he was after me asking some money... Then, my husband asked him 'What happened to that 2000 I gave you last week?' Father replied 'My foot!, you only gave me 20... You gave 1500 to daughter!' [laugh..] **Husband:** [laugh] **Interviewer: That's the nature of dementia... Isn't it?** **Main Caregiver:** He [husband] says... He [father] lies... and cheats me.	How the HCP provided encouragement and raised awareness among family members **PwD's concern and sense of being a burden to family/ sense of independence** (emotional abuse of the PwD) Care home is seen as a punishment, as something negative PwD's concerns - togetherness - dependency **Caregiver concerns-**

Control/lack of PwD's Autonomy & Freedom Vs Safety? **Togetherness** **Challenges of Care**	**Husband:** No… He has bought a lottery by that 20 rupees. In this area there are workstations. Many accidents had happened... Even last week someone had met with an accident. There are trucks which fly in high speed. He's got no sense... That's why we are afraid of him going to the road **Main Caregiver:** Yeah... Many lorries in this area... One boy got his leg broken last week... When lorries go they overtake the bikes and three wheelers, so people who walk aside the road meet with accidents… **Husband:** What we say is… 'Don't go… If you need anything, just let us know... We will bring that to you…' **Main Caregiver:** If something happen to him, while I'm alone at home? [she was worried and looks afraid of facing such event alone] **Husband:** He looks happy when he goes out though... [They told me that they are planning to take him a day out, but has not informed him yet] **Main Caregiver:** Didn't tell him yet… If told, he's awake from 2 -3 am, Many questions... 'At what time we are going? When we are going?' We accompany him if we go somewhere, but now we don't tell in advance. **Interviewer: does he usually wakeup after going to bed, at 7. 30?** **Main Caregiver:** No... only if he need to use the bathroom. No trouble in that. He can manage alone.	-Poor support from HCP and hospitals. -Preference for private channeling as the clinics are crowded -Not satisfied with current care/ treatment Challenge: PwD doesn't like the clinic, to be in crowded places/ becomes agitated and irritable Service gaps- receiving confusing instructions from the clinic Treatment is expensive, time consuming, some tests are available free of charge, but difficult to stand in long queues with the PwD's behaviour PwD has become more attached to the main caregiver and seems to be dependent on her. Both the PwD and caregiver seems to enjoy being with each other / bonding moments

	Interviewer: That means, he can switch on lights, walk to the toilet and return to bed alone? **Husband:** There are situations that he walks with no light… **Interviewer: Then? Do u keep lights on during night?** **Husband:** The day he passed urine outside, there was no lights on... We usually have a dim light on… **Interviewer: That means it's yet not a much trouble, Does that?** **Main Caregiver:** Dr. ASD once showed me a lady, much younger to my dad and said 'she can't recognise her husband even; this is the last stage of the illness… Let's try to control [symptoms] by medicine...' Father is now 88 of age. We don't know how long he will last, if he stays in this manageable state at least that's enough for me... **Husband:** He doesn't like to bother anyone. **Main Caregiver:** Now, today our son has scared him... When he troubles too much I too say… 'I'll put you into elderly home... If we can't keep you here.' Then he says… 'please don't... I won't go there even in my next life... Why? I haven't done any wrong to anyone?' He doesn't like to leave us. He likes to live with us. [Reflection: She seems worried telling such things to her father, later said she tells those when she gets angry for what he does sometimes...] **Interviewer: Has he been hospitalised before?**	Take the PwD wherever she goes as a safety measure/ not to lose him/ relief Uncertainty of future of the PwD **Anger – leads to guilt** Arguments among caregivers/ family **Illness perception/ Cognitive model?** **[Belief -** Poya day is for good work which gives merit **Assumption -** blaming father is a sin **Behaviour** – shout at father **Emotion** – guilt**]**

Uncertainty of future

Dependency

Emotional abuse/ hurt his feelings/ scare and threat

Guilt

Service Needs – clear instructions and guidance to caregivers **Challenges of Caregiving** **-financial burden** **-practical difficulties of taking the PwD to the hospital**	**Main Caregiver:** He has no any other illness... When I was a kid, he once hospitalised after an injury to head... He has flem, because of heavy smoking. That is the biggest illness... Nothing else… [Reflection: However, they did not attribute to these as causes of dementia] **Interviewer: In addition, has he been hospitalised due to dementia?** **Main Caregiver:** Last time he got agitated and started troubling us we took him to the [mental] hospital… We couldn't channel Dr. ASD... Then from the hospital we were directed to the dementia clinic… That day we couldn't keep him at home at all... I was planning to hospitalise him. But, doctor told they don't admit him at this age to the ward, but asked us to bring him to the dementia clinic... He was given more sleeping tablets… But the issue is, he doesn't like to attend the clinic... He's not comfortable being among the crowd... It was so difficult to keep him that day we attended the clinic. 'let's go... let's go...' he was giving us much pain.. It was because I had my elder sister with me we could keep him inside… **Interviewer: When is the next clinic date?** **Main Caregiver:** Once a month… We will take him next week **Interviewer: Did they ask to accompany your father, to the next clinic?** **Main Caregiver:** They didn't say either yes or no… Many tests to be done, before the next clinic… they cost about 9000 rupees... Then, they asked to do that scan to check the brain from hospital itself... We could have done the other tests also from hospital... but I was fed up, it takes time…	Sense of satisfaction of her caregiving activity Being role model How does the caregiving has affected the caregiver - limited freedom/ no time for myself - no way of going out - limitations to social and personal life events (social isolation) - vigilant Family support

Dependency **Meaning of caregiving: - Commitment to care** **Togetherness** **Challenges of Caregiving – Treatments/ weaknesses of westernised care model/ health care gap** **Stigma- Feel ashamed of PwD's behaviour** **Respect PwD's desire to go out**	**Interviewer: Will you bring him to the next clinic?** **Main Caregiver:** Let's see... However, If I go... I have to accompany him... He does look for me when I'm not there... **Interviewer: Aahh... I was going to ask the same…** **Main Caregiver:** I'm now devoted for him... Don't go anywhere else… If I go... he goes with me... One day, we went to buy fish from [the fish market]. When I go to the market… He accompanies me like a child... He really likes if we take him out… **Interviewer: Then how do you manage to get your work done?** **Main Caregiver:** When we get a three wheeler, I'll ask father to stay in three-wheeler [taxi] till I come back… So he spends time while chatting to the driver... I get to spend my day out... This way is much better than going out alone worrying about him... [The PwD came near to me... and was looking at me, smiling and being very friendly. Sat next to me.] **Main Caregiver:** Look here, he listens to everything... [Towards her father] 'We are talking about you... Dad!' **Interviewer: What do you think about it?** **Main Caregiver:** I ask them [family members] to accompany dad if others go to roadside... Daughter doesn't like, But son always takes dad with him... That's his desire you know... I think, how long we will be able to allow his happiness... Daughter loves him too... I	Caregiver's understanding of increasing of deterioration, forgetfulness over time. As a result, the PwD is disconnecting from his loved ones Caregiver's behaviour also cause disconnection Normalising the symptoms as his pesonality - he was misbehaving Now she seems to be worried that she misinterpreted her father's behaviour due to her lack of awareness how the diagnosis happened Potential family conflicts in relation to PwD's behaviour when PWD living with them -issues with taking permission from spouses to

Anger – leads to guilt Guilt and worry Control **Emotional fluctuations** of main caregiver **Meaning of Caregiving – appraisal/ encouragement** (Role captivity) **Caregiving responsibility and**	sometimes shout at him, when he relatedly ask the same thing.. I too get angry.. My daughter blames me, 'Are you nuts/ out of mind mother?... Seeya was not like that before.' Now, last Vesak poya day... he was doing a battle here! Insisting that he wants to go [his home town]... So, I sent him …. Next door almsgiving was also on that day. I couldn't even help them... I shouted at father a lot on that day... It was the poya day... 'What a sin is this... Thaththa because of you I made such a sin!' Then only I sent him to ayya's place.. [Reflection: I sense the **anger, frustration and guilty feeling** she had, having blamed her father.. especially on a poya day] **Interviewer: How do you feel after blaming him? Send him away?** **Main Caregiver:** When I send him away.... I feel so sorry for him… However, I sometimes think, 'When we were ill, he had never done something like I did...' But, when he's so irritable, I can't control him with soft talk... He doesn't listen. **Interviewer: Was there any change in your life after being the main caregiver to your dad?** **Main Caregiver:** At least, Dad got me... Even my sisters say 'If you were not there, *thaththa* is homeless by now...' I think, If I treat him well, my kids will see that... at least they will learn to care for me the way I did... **Interviewer: What else?** **Main Caregiver:** My freedom is now very much limited… There's no way of going out now... I can't participate in many occasions. If I go... I have to take my father with me...	keep the PwD in their household Arguments/ shouting Son and daughter both support in Care -talk on behalf of the PwD Lack of control/ stubborn Decision making on behalf of the PwD -plan for send him to an assisted living; guilt - decided to keep the PwD in family until he can remember (moral/ ethical/legal aspects of Care) (PwD's mental capacity/ inability to make decisions for him self/ best interest) Family tries to make the PwD happy, spend time with him

the sense of caregiver burden	Always I have to be vigilant, don't know when he'll run away... I'm always afraid that he'll get an injury... Now anyway he's not that fit like he was in early days... Day before yesterday, he fell down from the stairs... He doesn't even sleep well... Always walk sleepy… So, I'm super vigilant. [Reflection: Indeed there's a high risk that the PwD fall from the stairs, his bedroom was in upstairs and bathroom was in downstairs, and as they said he walks alone to the bathroom from room]	Spend family time with PwD, collecting memories. Giging the PwD happiness (quality of life) PwD's normal behaviour when he was in good health
Support-Sharing of responsibility **Challenges of Caregiving** Disconnection - **Losing the person/ losing identity of the person himself**	**Interviewer: How do the other members of your family support you?** **Main Caregiver:** If I need to go somewhere, I can send father to Ayya's home. I once went like that. Otherwise, I can't leave him at home with a stranger... He anyway doesn't like [to be with] outsiders... Father only likes his children... Among the grand-children he only like our son... He has now forgotten the others. Also, he only likes his daughters… He smiles and talks friendly with anyone, but can't recognise or recall who he or she is… Now, he knows us by our face, but can't recall our names… **Son:** He calls every one by the same name… There's one uncle who is his favourite. He calls every one by his name... **Main Caregiver:** Dad never blames my sister's husband [PwD's favourite]. Because of his bad mouth, many of them got fed up with him... Why he always, blames someone... He always finds faults of everyone... Never utter a word of good things [which they have done for him]	She compares how their attitudes changed with his recent behaviour changes 2 main Challenges: 1. wandering behaviour 2. Husband get annoyed with father's behaviour; it's a challenge to keep him in the house

Illness perception before the diagnosis – **Guilt** **Challenges of Care** **Challenge-Permission**	**Interviewer: Was he like this before? Or is it after getting the illness?** **Main Caregiver:** At the beginning of this illness… He was talking ill of us all... At that time, my elder sister's husband was dying... Father used to blame him even during that time... We didn't know that he [father] had this illness… We didn't know. **Interviewer: Did your attitudes change after you get to know he has an illness?** **Main Caregiver:** Yes... My akka's children. Sought medical advice from [name of a hospital]. Obtained medicine from a doctor… who also has explained the signs and symptoms... But father… when we tried our best to care... [hesitance, long pause] Now when he's at our place… my husband is really good for him [father talks good of him]. But when he was at Akka's place... he ill-treated him [husband] Now if they come to our place... he does the same to them... Now, when he ill-treats our husbands like that we also can't keep him at home... Can we? They get angry at us... That was the thing affected with many of us [for not being able to take care him as the husbands were angry at father's ungrateful behaviour]. I had the same issue earlier... Now, I have made his mind [with much difficulty] to keep father at my place… **Interviewer: Have you ever had conflicts because of this?** **Main Caregiver:** He sometimes shouts at me. I keep aside... However, I have to manage both the situations, you know! [Laugh] **Interviewer: How does Your Son and Daughter reacts?**	Husband's perception about the PwD, illness, caregiving and his anger towards other relatives – shows his displeasure to have the PWD in his house Misunderstandings and Lack of awareness - How the family members interpret PwD's behaviour changes Repeatedly said that the wandering behaviour is the biggest challenge they have Husband's concern of his wife being the main caregiver Involve the person with dementia in family activities PwD may feel productive/ included

Support **Challenges of Caregiving** Meaning of caregiving - altruism **Ethical/legal aspects of Care Connectedness - Togetherness** **Guilt – sending away from home/ being unable to take care him at home/ dependency of the caregiver** Togetherness	**Main Caregiver:** Both of them are very supportive. Very friendly with *seeya* [grand father]. Even If I shout at him, daughter blames me 'Have you lost your mind amma! It's because of his age!' But she doesn't talk much. That's her nature... But Son, stays with him, teasing... **Interviewer: What are the challenges you have when caring for your Dad?** **Main Caregiver:** He is stubborn… Never listen to us. That is the trouble we have when looking after him. Otherwise, I'm caring for him with much pleasure… He is clean, and doesn't like to be unclean. **Interviewer: Do you like to keep him with you till end?** **Main Caregiver:** Yeah! If he was in good condition… So, doctor also once told he will find us a place, if there ever comes a day that we can't keep him at home. The social worker we met at the clinic gave some information about payments to be paid in few places. So… If there is a situation that he can not recognise us.. or out of his mind totally… **I have to send him** to elderly home… If not… when he can remember us… it's a sad thing to send him away. Look there [pointing towatds the PwD]. He likes to enjoy. [Reflection: He was sitting near us, playing with my car keys and my phone... which were on the stool] **Husband:** Recently we took a picture of him wearing a full English suit. He had never put on a trouser before... with that dress he came out. he behaved like a real Englishman… [he acted]	(respect PwD's emotional needs) Husband's perception towards dependency **- self-respect and dignity of the PwD** **- need for PwD's Independence/ lack of identity as a person** -Poor drug compliance -need for vigilance Health care access/ issues and challenges -appreciates current treatment - A common reason for caregivers to give up western medication, and treatment

Support-finantial and otherwise	[Reflection: Her son showed me a photo of the older person in a full English suit, wearing sun glasses, smiling happily] **Main Caregiver:** Yes... he spoke like a foreigner and danced. It was fun! He likes to dance. **Interviewer: Were those habits there from the beginning?** **Main Caregiver:** Yes, indeed. From the known times he likes to enjoy… When we were at *mahagedara* we haven't had any meal alone... Always we had a visitor. He found a room for homeless couple and paid for them until they found a place to live. There were four such families known to me who had immense support from father. even though he helped people when he was young. After getting this illness he behaved in a way that people were frustrated on his work. Not the outsiders… even his own children were fed up on him. **Interviewer: What do they tell now?** **Main Caregiver:** They now pass merits to me... for what I do now... **Interviewer: Do they help you? In what way?** **Main Caregiver:** Yeah.. My younger sister sends 10,000 rupees each month… If there's an emergency, I can send him to their place... I have no other troubles. We can't keep him in one place, and my father annoys him [her husband] by telling that and this.. Those are the issues… **Interviewer: [towards husband…] Have you understood his situation now?** **Main Caregiver:** Yes... Now he is... [Laugh]	Financial burden of caregiving Generosity of them towards me_It is the Sri Lankan culture Ironically he said, no one visits father now?? Hide things from husband to avoid conflicts and resistance to keep father at home Eg: father's behaviour Support from taxi driver as rest of the family members avoid their responsibility

Coping mechanism- stay away from the PwD to avoid disagreements with him **Illness perception -Attributing the symptoms to normal behaviour** **Permission** **Challenge - wandering** **Engagement**	**Husband:** I don't talk to him now... If I talk only the issue comes. He tells everything, even speak ill of her [wife]… Complaint about others for not coming to see him... Recently he told me, 'You're the only one who got some brain!' I thought, It's better get aside rather than chatting to him…' He comes and asks me 'I want to go out, will you help me?' then I tell… 'Ask your daughter... she's there.' **Main Caregiver:** In the early days, during the onset of illness he was lying. Telling tales that created issues in those families. He did such things... He was at Akka's place... It was the onset of illness, but we didn't realise... it's because of this illness… **Husband:** Telling tales to that side and this side… **Main Caregiver:** Father doesn't like it well when we daughters get along well with our husbands… He wants us to pay full attention on him. That's why he tries to get attention towards him even by telling tales or lies. This is the problem. **Husband:** That is why he got kicked out from other places. This was the problem. I told her. With mercy... 'It's ok let him stay with us... I too got parents… Let's keep him with us and see... Perhaps we can lock the gates.' The biggest issue with him is he's wandering. Otherwise we have no any other trouble... When Son goes out she's [wife] lonely at home.. So she can't go out and be bothered looking for him each and every time he runs away! **Main Caregiver:** He [husband] usually comes home [from work] after about two weeks... Because he's a tour guide... But, if there's no one at home he doesn't trouble a lot…	Lack of space/ poor household arrangements to keep the PWD Waiting list for consultation (even private sector, paid care) Lack of freedom/time for family as a result of role captivity. Caregiving is a continuous learning process with gradual deterioration of the PwD Confusion/ Lack of awareness/ Uncertainity of future behaviour of the PwD The interview itself helped a lot to raise awareness about dementia among the family members. It also was a relief to the main caregiver

Concerns related to dependency of the PwD **Challenges of Caregiving** - poor compliance **Service Needs**	**Husband:** When our son does the cooking, He involves him… 'Seeya.. Can you chop the onions for me?' He does that… **Main Caregiver:** He loves to help… Eat very little during meal time... **Interviewer: Perhaps... The amount he eats may adequate for him... Isn't it?** **Husband:** Other thing… That's a disgrace for him. The biggest thing is… he thinks 'Why would I eat for free here?' That's why he tries at least to sweep home… That's my opinion... He told me 'I don't like to idle at home… Me being here looks like a trouble to u...' I told him, 'It's not a problem at all…' **Main Caregiver:** Here… even yesterday he got ready to go looking for a job… **Husband:** He asks… 'Aren't there anything [drink] towards evening?' [laugh].. I used to buy him a drink earlier... now I quit doing that. **Main Caregiver:** He doesn't drink much..! Drinks a little when give it in a glass.. But medication... He throws them away if I'm not near him... I watch till he swallows the pills. Otherwise throws it away. **Interviewer: He got caught doing that?** **Main Caregiver:** Yup! Since then I do not move till he drinks it all. **Husband:** He is like, 'Why would I need drugs? I haven't got an illness... Are you the doctor?' **Interviewer: Tell me... What facilities/ support do you have currently to lookafter him? I say, like health care facilities?**	Never heard the word 'dementia' Denial of symptoms- Husband still thinks PwD has a good memory and he's pretending to be forgetful. Main caregiver was told the possible deterioration by the doctor. But her husband remained in denial. Ethical or moral aspects of care - Giving up on caregiving - Mental capacity of the PwD may lost by this time - Guilt of sending him away in his last days - Stigma - Helplesness

- **Dementia-friendly clinics and easy access to care, facilities** **Sense of burden - finantial** **Social Isolation – due to stigma/ avoidance of responsibility** **Challenges of Care**	**Main Caregiver:** So far, he gets his medication [not difficult to give him pills]. Actually, the medication from government hospital is better... But the issue is the waiting at the clinic. Father doesn't stay at one place such longer... That's the very reason we were reluctant to visit government hospitals. Doctor asked us to get all the blood reports from the hospital it self… But, because we can't keep father that long, we came back. But it's very expensive to buy them from outside pharmacies. Then travelling… We can't take him by bus you know. Always three-wheelers... So many expenses. It doesn't matter if we could keep him… I'm now thinking [what bothers me right now] how to keep him there when we visit the next clinic… [Reflection: I felt sorry for her... Seems there's lot in her plate right now and she manages many things alone… Meanwhile the PwD leaned towards me and asked, 'Shall we have some lunch?'] **Husband:** We are much happy if someone visits us and see him. No body comes here often. [He went away for a while, the maincaregiver started speaking softly] **Main Caregiver:** I have to hide some things from him [husband] also... Every time my father became irritable he was not at home... [Reflection: it sounded like his absence was a relief to her...] He was here only once I guess... He [husband] gets angry... It's my son who stands for me... We both get together and manage the situation. **Interviewer: Who do you talk to in an emergency?**	Plan to send him away if the condition gets worse Institutionalisation is their last option Lack of resources/ information In Sri Lanka we don't have family nurses/ community nurses/ social workers who visit families and support in caring for people with dementia There is an information gap No any other cultural practices other than pray for wellbeing and good health.

Support **Sense of Isolation – avoidance of responsibility** **Challenges of Caregiving –** **Sense of Burden** **Meaning of caregiving - Learning**	Main Caregiver: It's my brother... My little sister can't help… She is ill.. So it's *ayya* whom can reach for help… His wife also so good... So concerned always... [Kithsiri returned and joined the discussion again] Husband: Even he [brother] doesn't visit him often... [sounds angry] [Reflection: I felt like Mr. Daniel really expects other siblings to visit the frequently and care for father, He's angry at them for not doing so] **Main Caregiver:** They don't come here to receive father… I send him in a three-wheeler.. even if he goes… stays there maximum two days. **Husband:** At least he can walk in our yard here… They live in a flat... **Interviewer: If you need an advice to whom you speak to? Can you reach your doctor anytime?** **Main Caregiver:** It's not possible. We even cannot channel Dr. ASD whenever we need. That's why we took him to [mental hospital] that day, But… Something good came out of that. **Husband:** Now, we even can't go somewhere whenever we need... Why no one is willing to accept him [even for a day]… We have such a problem too… **Interviewer: Now, by this time do you have an understanding about the illness?** **Main Caregiver:** No... we are still learning... Now, he wears a towel around his neck. He was not like that earlier. Sometimes… two towels in either sides… If there's no towel he wears anything around the neck... He can't live without this…	[Disinhibiting behaviour changes of the PwD] Behaviour changes of the PwD make it more difficult to keep him at home. She hid these from her husband as she was afraid she may have to send her father away from home. even though main caregiver is aware of the nature of

	Interviewer: What sort of support you expect from health sector in relation to providing care for a person with dementia? What do you expect as caregivers? **Main Caregiver:** Now… I don't get that angry at father just because I'm his daughter… It's a very good thing you came today even like this…	illness she can't make others learn that without professional help.
Service Needs: Educate family members about dementia, its signs and symptoms	During meal time he washes his plate, gets his water glass by himself, has his meal nicely sitting in this table... Now, all these activities are done mindfully, you know... He can recall all the old memories… When he does certain things properly like that. They [her husband and other family members] get angry... Thinking that he is lying to us... They get angry because they don't know/ have no idea about the disease... When you raise awareness among the family members like this… we all get to know things… That's means a lot!	Positive impact of the interview – educating caregivers Guilt of not being able to detect the illness before
Lack of Awareness about Dementia	**Interviewer: That's good to hear. Have you ever read about this illness? Any information (like leaflets) given from the clinics?** Main Caregiver: No. **Interviewer: Did you ever search in internet? Any other source?** **Son:** It's only today I learned the name of this illness. **Husband:** I too… It's only today I heard the word 'dementia…' But, he doesn't have that... At times... he can recall very old things... [Reflection: Mr. Kithsiri, sounded like he's not yet willing to accept] **Main Caregiver:** That's the nature of this disease. How many times I have told you!	How the family members reacted before the diagnosis of illness - PwD's behaviour was irritating to others - Anger towards each other

Need to Educate the nature of dementia **Illnes perception - Denial** **Connectedness? Decision making on behalf of the PwD** **Sense of Burden -guilt**	**Husband:** Come on! He has a good memory… Now think. He woke up in the morning, had his tea, got a sarong… Went to bathroom… Had a shower… [long pause] But, there are times that he wears his used clothes… [Reflection: He seems, not believing that his father-in-law really suffers from a memory loss... He thinks he occationaly pretends to have a memory loss...] **Interviewer: Have you got an idea about the behavioural changes that might appear in future? Did anyone tought you about that?** Main Caregiver: Yes. Dr. ASD told… like I said earlier, 'Sometimes he won't be able to recognise me...', [looking down, low tone] **Interviewer: Are you ready to face that time?** **Main Caregiver:** Yeah! If he lost his consciousness to that level... I said, I will send him to a nursing home... He won't recognise us then... We also will feel no pain... Won't we? He doesn't know where he is... I mean, If the situation gets worse... I have to send him... [Reflection: This seems so unfair by the PwD, when his mental capacity was gone family decide to send him away. His wish is to be with the loved ones, I felt so sorry for the PwD. As a daughter the main caregiver may also feel guilt for not being able to look after her father. But with the resistance from her husband to keep him at home and lack of support from other siblings she may not have any other alternative.] **Interviewer: Have you got anything else to be done? Or something which I may be a help?**	- Passing the responsibility of care to each other - Autonomy Vs safety of the PwD - Lack of awareness lead to neglegence Caregiver concerns: Helplessness/ financial insecurity/ difficulties with decision making as the main caregiver/ feeling guilty for not being able to provide better care Coping- Share feelings/ emotions among the sisters Long queues in hospital Dementia friendly clinics/ health services required Gender of the caregiver is a challenge at times

Connectedness – belongingness, volunteering/ commitment to care **Service Needs: Support Caregivers**	**Main Caregiver:** Tell us about such places please... Better to find a place if there ever comes a day… Other sisters discussed to send him to a nursing home much before... Even that day we attended clinic akka asked the doctor... 'It's difficult to keep him at home'. Doctor directed us to the other person to talk, that thin one [social worker]... But I was telling my sister... 'Still father can remember, he's conscious yet.. will place him in a such place, only if we have no other way.. I'll treat him, let him stay with me... I can look after my father...' [I told them about the Lanka Alzheimer's association.] **Main Caregiver:** There's no way that we can get information... That's why people like him are helpless… Can't keep them at homes at all… **Interviewer: before you start proper treatments, did you try other alternatives? Like devil dancing? Bodhi pooja?** **Main Caregiver:** Father does not believe in any of those... He is an atheist. Never goes to temple. Does not wear chanted threads... My husband is a Catholic. I'm also now converted. So we also do not believe in those. It's our son who prays in the evening... Father looks at that... Son gets the incense sticks near to him… then he [father] says his own prayer... 'ඉර බලා.. හඳ බලා.. මා බලා..' [she imitated few words which means something like, 'Sun, moon will lookafter me…']. Then son says, 'all your sickness will be cured…' **Husband:** He blesses himself… Tells 'all success..!'	Afraid of PwD's behaviour Due to lack of awareness/ not being able to take responsibility Concerns of other family members – ashamed of PwD's behaviour/ illness, lack of their freedom, disputes Husband's concerns and pressure on Caregiver Main caregiver's life seems to be out of balance and not interested looking after her health Fear and uncertainty of future of main caregiver/ PwD and the family as a unit Perspectives of the family members living with PWD - Main caregiver doesn't feel caregiving as a burden but her husband feel it more

Challenges of Caregiving **Fear of disapproval/ rejecting the loved one by other members of the family** **Caregiver Challenges** **-PwD's behaviour**	**Main Caregiver:** Now, even when I offer him food he says 'tripple gem may bless you…' But, he never goes to temple… On poya days now, I can't keep him home at all. He makes poya as an excuse, pretending to go to temple… I think he doesn't even know the stanzas.. He liked living a fun life, but was not religious… **Husband:** Here… Rani.. Tell her everything! I' m also listening [That tone sounded angry... It sounded like he knows that she hides something from him...] [Reflection: Mrs. Rani was uneasy, and I felt she wanted him to keep out from our discussion. She gave the information leaflet to husband and asked him to read it, so he went out for sometime... Main caregiver appeared not free to express her feelings in front of her husband] **Main Caregiver:** I can't tell you now, [very low tone…] He [the PwD] sometimes troubles women... He once tried touching [inappropriately] my daughter when she was sitting on the sofa... two or three such incidents happened like that... we decided not to tell him [husband] as I was afraid he won't let him stay with us anymore. [She was reluctant to discuss this topic in the presence of her husband... So I did not want to ask more...] **Main Caregiver:** I don't think he knew what he was doing. But, it's not nice. Shame! That is the reason, other sisters do not want him in their houses. A neighbour once shouted at my younger sister... My hsband doesn't know those.	- For grand children being with PWD is fun - For PWD being with family is happiness and joy - Extended family members (siblings/ in laws) it's a shame to visit their house/ PwD's behaviour is shameful/ have abandoned PwD and the family, and avoid them Moral/ ethical aspects of care -being ungrateful Reflecting on the meaning of life

Service Needs: Support/ home visits by a professional to educate families and caregivers, empowering	**Interviewer: May be he doesn't behave like that deliberately.. Those behavioural changes may be due to the illness too..** **Main Caregiver:** Yes. Dr. ASD also told me.. Gave examples too... But, I can't educate all of'em [family] regarding these... Some will never realise… [Reflection: Husband returned, so she was reluctant to talk more about that topic... I saw the sense of helplessness and fear in her eyes…] [long silence] **Interviewer: How do you feel about talking with me?** **Main Caregiver:** I'm so happy... Learned a lot from you. Actually, It's so nice if you can come again like this... Father suffered a lot because we didn't have any idea about his illness… Now, let's think... if father had this for more than 2 years... it's like only about 8 months since we started medication on him. If we knew this could be a disorder early, we could see a doctor earlier, we could start treatment earlier than this… Finally, when all were fed up with him only we started medication... [Reflection: I felt like she is having a guilty feeling of ill-treating her father by all her siblings] **Interviewer: Then, before obtain medicine… Did you all think he was deliberately behaving like this?** **Main Caregiver:** Yes... He was not with me at that time... He was with my nangi, or else with akka time to time	Connectedness (negative) - Avoiding the responsibility Relief - Effect of the interview - Support – awareness - empowerment

Journey Experience **Dependency of the caregiver** **Support needs - finantial** **Guilt & frustration** **Support – Emotional support**	**Husband:** But, those days he [the PwD] was more independent than this... Even traveled alone… **Main Caregiver:** He used to get angry at my nangi, and goes and stays with akka… when he gets angry at akka, goes back to nangi.. That's what he was doing… Then, we never thought he has this type of an illness... In fact, he was not depending on us.. If he ever come to us, only have one meal... He was smoking, travelling… all by his own money.. **Interviewer: What sort of support/ help you wish to obtain from others?** **Main Caregiver:** I'm not doing any job... So I have to ask him [husband] for everything [money]. But I don't ask for father's expenses from him... If I had some kind of income... I could have stand for his medication and travelling... We could have gone on a day out… you know, things my father likes to do... Now, I spend what my younger sister sends to me on his medication and other things. **Interviewer: Only she sends you money?** **Main Caregiver:** My elder sister also supports me financially as she could… She doesn't do any job either... It's not that they don't love father… But, everyone just can't keep father with them, they have their own problems…[She reflected on the challenges of other siblings not being able to care for father] **Interviewer: Other than that, is there any one whom you can talk to when you want to relax your mind?** **Main Caregiver:** Yes, I use to call my sisters… and tell. Even if I haven't got cash for his medication I call them…. They help as they can…	

Service Needs – dementia-friendly service Improvements of Care - Clinic setting - Availability resources **Support – neighbours but there're limitations of support** **Sense of burden – Shame** **- Anger Frustration** **Service Needs – educate family members regarding the nature of illness**	**Main Caregiver:** I just don't like to stay in hospital queues. **Interviewer: It's not compulsory to bring [the PwD] to clinic every day, Is it?** **Main Caregiver:** Only in first few visits... Then I can go without him... But even If we take his reports with us... there's a queue... A patient like him cannot wait at such a crowded place... He wants to use the toilet so often. We can't send him to the toilet alone, but they are male ones we ladies can't go there... By the time we come from the toilet our place has gone [number is called already]. **Interviewer: Do neighbours help you?** **Main Caregiver:** Our neighbours are really good... But we can't leave him with them. People are afraid to look after him with this type of illnesses... If they saw father is running away, they inform us. **Husband:** We can't do this every day... Now, I too have parents. I must take care of them too... My parents never visit our place because of him... I couldn't bring them to this house and arranged a meal yet... [He sounded angry and frustrated] **Interviewer: I can Understand your situation.** [Reflection: Mrs. Rani was uneasy when her husband started talking that way… She tried to change the topic... Her husband seems so unhappy about father-in-law living with them and about the fact other siblings do not play an active role in caregiving.]	

Challenges of Caregiving – Family conflicts **Living with a PWD affected other family members' social lives/ personal lives**	**Husband:** They have work... So do we… We also go to job… No time to come… [the relatives].. I can't tell things every day... [That he's fed up explaining things to wife/ relatives] Because of these, there are issues in this house... [sounds angry, high tone] [Reflection: Since my main caregiver was nearly crying. According to Kiithsiri, caregiving has affected the lives of other family members and the way he sees, the meaning of his life. I thought better to change the topic. Otherwise it would create a situation. Perhaps, I may meet her another day, so we can talk more openly than now. So I turned to her and asked about her health] **Interviewer: Now, are you on treatments for anything?**	
Lost time for yourself **Caregivers health is a challenge**	**Main Caregiver:** Yes, I'm on Thyroxin… I've got high blood pressure... I have no idea what else... I don't check... [smiles] **Husband:** Yes..! Now what I'm supposed to do if something happens to her… because, I too have undergone a surgery... I've done a mitral valve replacement. **Interviewer: When was this?** **Husband:** About 2 years back **Interviewer: A…hh!**	
Changes to the perspectives of one's personal life **Concerns of the Main caregiver -not that burdened being the main caregiver to PWD**	**Husband:** It's good if other children also visit him time to time... At times I too think… How will my kids will treat me if such a thing happened to me.. **Interviewer: Hmmm.. Mrs. Rani, Can you spare sometime for yourself with all these work?** **Main Caregiver:** I am not that troubled/ burdened... Therefore, I don't care about it much...	

Caregiving as a Positive experience – Pleasure/ Joy/ Happiness being with PWD **Connectedness** Relationship between each other **Togetherness** **Connectedness Vs Avoidance**	**Interviewer: How do you feel being with Grandpa?** **Son:** I like very much... Being with him is full of fun.. he is hilarious. [I felt like he makes fun of the PwD, amused by his behaviour so likes the company] **Main Caregiver:** Even his friends like him, When they visit us they treat him well… **Son:** Grandpa lives happily, joyfully. **Main Caregiver:** Anyway, father likes very much to be with the ones who are younger than him. Mother used to tell, he's trying to become a teenager... [laugh] **Interviewer: How does your daughter respond?** **Main Caregiver:** Ane... She loves him very much... They both have very good understanding... So, I'm at ease... [But during the conversation she was reluctant to speak on some points, as her husband was there... It seems she hides certain issues from her husband…] **Son:** Among all other kids in our family, It's my sister and me who loves grandpa a lot... We very much like if he lives with us longer... Others even do not talk with him much. **Husband:** Other thing, He can't remember them now... Only remember our sons name... **Son:** There are other grandsons who got more benefits from grandpa.. Now they don't even look at him. **Main Caregiver:** Father wrote our 'Mahage' [paternal house] to the son of brother who is in Galle. Now they don't even bother to call asking his health. **Husband:** He loved their children a lot in early days... Now there's no one...	

Connectedness – caregiver and researcher/ health care workers	**Main Caregiver:** It happened to him today... This could happen to them tomorrow… They haven't think yet... I guess…That's why... **Husband:** They have forgotten grandpa now… [Reflection: The PwD was playing with my car keys… throughout the discussion.. time to time he was smiling at us.. Communicated with Mr. Kithsiri using body language (hand signs and rolling eyes...) He seems to enjoy the time with the group.] I spent some more time chatting with them on random matters... and left their home...] **Main Caregiver:** Thank you very much for coming. It was a big relief talking to you. Talking itself a much help for us.. Come again.. Is it OK if I contact you back? **Interviewer:** Thank you very much for your time and this opportunity to talk with you all. If necessary, you can contact me by calling the number given in information leaflet. [Reflection: The PwD wanted to accompany me to my car.. So they allowed him to come out from the gate... His grandson was following him... I waved goodbye to all... and came back to office... Later Rani called me back and asked me to come back to her place for main caregiver interview, as she wanted to '*tell me more'*]	

Appendix 14-B: An example of an analysed transcript (A main caregiver Interview)

REC No: 180415_PWD26_MI_14

Participants: Ms. Samanmali (Main Caregiver), Interviewer (KA)

Date Interviewed: 15/04/2018

Venue: Participant's home

Time: 01 hour

Transcribing time: 09 hours in Sinhala

Translating time: 05 hours

Themes/ sub-themes	Transcription	Interpretations/ Condensed meaning units
Responsibility: Main Caregiver is the PwD's sole support	**Interviewer:** Good morning miss. Shall we start the interview with some of your normal information? Like your name, Your relationship to the patient? Some information about your family? **Main Caregiver:** Well, it's okay. My name is Samanmali. Age 55. The patient is my mother... Ahh.... It's just me and my mother are in the family. **Interviewer:** So, What about your job? **Main Caregiver:** Ah… sewing clothes. [An entrepreneur]	Only the PwD and the caregiver are at home. Maincaregiver is Unmarried **Sole responsibility of Caregiving Lies in her shoulders**

Illness Perception **-lack of awareness** **-poor insight** **-behaves like a kid** **Commitment:** **Engaged in long term Care** **Togetherness** **Challenges of care** **Meaning of Caregiving: control of PwD's behaviour** **Sense of burden** **PwD's need for autonomy?** **Challenges of Care** **-wake up early** **-stubbornness**	**Interviewer:** How long have you been caring for your mother as the main caregiver? **Main Caregiver:** Mm... I do not remember exactly that for years ... Now I'm 55. Mh… [laughs] I've been [caring for her] since I was like 20 years old… So, it's usually about 30 years now, isn't it? [Reflection: She calculated the years which she was looking after her mother as a daughter. I think she refered to her responsibility of taking care of parents, not caregiving for PwD] **Interviewer:** Hm... How much time do you spend with your mother in a day? For how long do you engage in her care? **Main Caregiver:** Ah.... it's like... [thinks] You have 24 hours per day... from that I spend about 10 to 12 hours with her, rest of the time I do other work... like going to the shop or market… [these also related to her day-to-day activities] It's only when I go out from the house she can't be with me... Otherwise I am continuously at home with her… **Interviewer:** Can you explain me how you spend the day as a caregiver? **Main Caregiver:** Oh, my day... [pause] Now, Amma ususally gets up early in the morning, like half pass one... [smiles] Then... she starts her chores… She puts the kettle on heath... boils cowpea... She wants to do all the work [by her self]... but she really can n't do now.. No matter how much I asked her not to, she is near the fire all day... Sometimes I feel like I'm baby sitting. She is like a kid at age 3 or 4... She is always stubborn... She does exactly what I ask her not to... and she's not doing what I ask her to do... Now… [for example] let's say religious activities... I'm trying to get her involved in those... But she's not happy to do those...	**Long period of caregiving/ even before the pwD become ill she was loking after her mother** **-total caregiving over 20 years** **-nearly 2 years after onset of dementia** **10 – 12 hours of a day is spent with mother** This suggest commitment and also there is a risk of caregiver burden **Lack of sleep for caregiver as well** **Risk of injury/ burn** **Role reversal – daughter has become 'baby sitter'** **The PwD gets up so early in the morning, difficult to manage her behaviour, risk taking**

Meaning of caregiving: Control of behaviour **Illness Perception and Lack of Awareness** **Influence of being a Buddhist on caregiving** **Sense of BURDEN- Disputes between PwD and Caregiver** **Meaning of Caregiving: Caregiving is Controlling the PwD** **Blame/ Punishment**	even if she does, that's without proper understanding... like a habit of doing… she doesn't know what she's doing… [Reflection: She didn't sound like to have a clear idea of BPSD. But she has recognised her mother's lack of orientation to her daily activities and strange behaviours which are 'not normal'] Now she behaves like she's in her thirties... Most of the time ... not always... Sometimes she says things that I really do not know… Things that had happened even before I was born... Somehow... now she's at that level. Her memory is too weak... Sometimes she remembers things well... Sometimes... Meh.. Her memory is low... **Interviewer:** Hmm... Do you have any special events [related to forgetfulness and BPSD] share with me? **Main Caregiver:** Especial events mean... I often face such situations... I can't exactly remember when... Now, most of the times, I ask her to take refuge in Lord Buddha… [Think of the qualities of Lord Buddha] Sit down and think about it... Now, as Buddhists it's not that hard you know... But she doesn't listen to that, instead goes out and plucks flowers. Not because she has an understanding of what she is doing, she's afraid someone else will pluck them before her... All in a fist, flowers, buds all… At times, she seems conscious… She says [to me] 'you are blessed by Lord Buddha' and blesses me... pass merits for caring her… But also shouts at me sometimes... Says, she doen't	**The PwD seems not happy to follow instrauctions of the caregiver** **The caregiver recognise/ notice the symptoms of dementia, but it appeared that she had no idea that it's due to dementia/ or an illness** **Her caregiving seems much influenced by Buddhist concepts; She is a religious person and wanted her mother also involved in these.** **Caregiver's religious beliefs affects with the control, makes PwD angry** **Qualities of a caregiver** **Seems her mother's *stubbornness* bothers her much – Sense of burden?**

Relationship issues **Meaning of Caregiving : Learning to be a caregiver/ skills and Cope** **Identification of causes** **Lack of awareness** **Lack of awareness about the nature of illness (challenge to caregiving)**	want children like me… Scolds me… So, one would need much patience to deal with such occasions [she talked about her efforts to tolerate and cope with her mother's behaviour] Actually... I have made my mind thinking of Dhamma facts. Or else, it's difficult to be with her. It's easier to lookafter a little one at age of three or four years than looking after her. That means ... it's easy to control and stop them when doing something wrong. But this is not like that, you know… I can't blame her... Can't punish... can't say anything... Now, in many times she [is not doing the right thing] I… Say if I ask something… she does the opposite... Sometimes she is very good... [Pause] Sometimes she sleeps well... Now yesterday, she slept whole night. What happens during most of the other days is she gets up around one or two in the morning, again takes a nap around 4 in the morning… She sleeps during day time and wakes up during night. **Interviewer: Hmm…** **Main Caregiver:** Most of the times I think... She is lonely as she hasn't got anyone to talk with [except me]. Now when she's with kids [neighbours] she has no complaints... It's because of her loneliness she acts [as I said before…] [Reflection: I think she refered - it is the loneliness that brings all the sickness and complaints]. Now, when her sisters visit her she is so happy... The other day, they were chatting and laughing about the things happened when they were in their thirties... She likes to live in that age… [she repeats] like those days… [Reflection: It appeared the caregiver did not recognise this behaviour as a symptom. So far she didn't refer the behaviours as symptoms of any illness]	**Caregiver appreciates PwD/ but there is lack of appreciation of the caregiver by PwD (blame/ scold)** **She thinks mother's behaviour/ complaints are resulted by her loneliness** **Deliberate act/ lying – denal of symptoms** **Misinterpretation of BPSD**

Illness Peception **- She lies** **-pretending to be forgetful** **Challenges of Care** **-food refusal** **- nutrition and hydration** **Control – force to have meal** **Vigillance** **Sense of autonomy** **Meaning of Caregiving- Control, decision making on behalf of the PwD**	**Interviewer: Hm... how old is she now?** **Main Caregiver:** She is 83 now. **Interviewer: Now earlier you said she complains about illnesess. Can you tell me more about that?** **Main Caregiver:** She complains about poor vision... leg pains... She says she can't see any thing... but she sees my grey hair... [it sounded so sarcastic, she had a smile in her face. I think she does not trust her mother's poor vision]... She lied many times... [she seems not believing in her mother's complaints of leg pain and poor vision] **Interviewer: Like what?** **Main Caregiver:** Like my grey hair… She says it's grey because she can see my hair, right? Sometimes... [pause] she refuses meal... [Reflection: This is a common complint repeatedly heard from many caregivers. Caregivers used force to feed PwD sometimes. Perhaps PwD's BPSD, dependency, physical inabilities may result in refusing meals] However, she is not like others... [she compared with other elderly people in her area] Even if I haven't given her any thing to eat, she says she just had her meals. Now, oneday a salesman came here... I heard, she tells him.. 'I have no escape from this child... Always she offers me tea [with milk]... I can't even drink that much...' [laugh] I haven't given her tea as she said… Now, that's a lie again… **Interviewer: Hm…**	**Caregiver does not recognise the patterns of Behaviour/ personality changes which are also early signs and symptoms of dementia (challenges of lack of awareness)** **She seems to give up/ fed up and stopped giving her milk anymore (a result of continuous refusal – sense of burden/ frustration?)** **Caregiver concers** - **About PwD's food refusal** **Comparision with other older adults known to caregiver**

Challenges of Care **Illness Perception** **-lack of awareness leads to normilising of behaviour changes** **-poor insight** **-behaves like a kid**	Earlier I only gave her tea [with milk] in the morning... and at some nights too. I stopped that because she doesn't drink it... No use of wasting [money]. She either throws it away or feeds the cat when I'm not looking at. If I went away for a minute... she feeds the cat. [challenges of feeding – nutrition and hydration] Now I don't buy her milk... But, I often give her porridge... she likes that... But if I'm away or didn't force her to drink, she throws that way... Have to keep eye on her.. even drugs are the same.. She doesn't like when I feed her... She wants to serve herself... She says she will eat by herself and throws them away... [Reflection: she seems worried about her mother's behaviour] She doesn't eat well... Eat very less amount at a time... she likes to have only lentils and buiscuts. She doesn't like any sweets... or cakes... Not like other elders... Never eats cream crackers or lemonpuff. **[Reflection:** Many caregivers complained about food refusal. This is a common challenge for many caregivers; What can be the reason for older adults to refuse assisted meals or forcing them to eat? Perhaps PwDs' **feelings of autonomy and indedependence** prevents the PwDs obtaining assistance for these minor activities. However, it increases caregiver burden and concerns towards wellbeing of PwD] **Interviewer: Now, earlier you said she forgets things... What type of things she forgets usually? Please explain me more.** **Main Caregiver:** Forgets means... She can't remember her meal times, even her tea time. If I didn't give it to her... she doesn't remember whether she had her meal or not... Now, let's say I gave her tea after two hours [of the first cup of tea]... She says, I just had my tea... I have	**Forgetfulness is often interpreted as PwD is lying or deliberately not doing something** **Increased dependency -sense of burden** **Shows significant lack of awareness about S & S of dementia:** **Caregiver noted the forgetfulness, but do not recognise them as symptoms of dementia** **Neglegence of emotional needs**

Meaning of Caregiving **-duty** **-no attachment** **-a reciprocation** **-follow buddhist teaching to care for parents/ ill** **Challenges of Caregiving:** **No time for self** **Meaning of Caregiving** -commiment -Duty or responsibility **Sense of Burden**	to remember her meal times. I have to do everything on behalf of her. [She sounded like she need to do all the decision making on behalf of the PwD, as the PwD is forgetful, which she misinterpreted as PwD's lack of responsibility] **Interviewer: hmm..** **Main Caregiver:** She can't remember anything in recent past... She only remembers things happened in her thirties... She likes to be with kids... [Reflection: before I started recording the interview she told me her mother used to baby sit the neighbourhood kids sometimes back, according to her memory it was before 15 to 20 years. And she loved being with kids] Now even in TV she likes to watch kids' programmes. Near her bed, there is a calendar of a kid... an old one. She talks with that kid... [smile] asks, 'Why are you laughing at me... Can't you make my mosquito net?' [Reflection: She smiled when she recalled this memory... She seemed enjoy her mother's child like behaviour] Chuh! She has a child like mentality now... I think that's why she likes to be with children. Now, when that neighbourhood kid comes here, she spends time talking to him... I heard... He can't understand a thing, but she was chatting about her old days... [Reflection: She sounded like, it's useless to talk with her mother. Seems she is not interested to listen and understand the PwD's mentality. She always mentioned she behaves 'like a child'. This may associate with the way she interprets her caregiving role as controlling her mother's behaviour, as baby sitting. This may also affect with losing PwD's autonomy and decision making ability at some point.]	- PwD's emotional needs to communicate what she can remember. But the caregiver seems not interested to listen to her **Not attached, just as a duty** **Sense of Burden** - **Lack of time for self** Sense of burden? -I have to be with her (No much choice left for her) **-Devoted for caregiving, but not willingly**

Challenges of Care **Meaning of Caregiving – Controlling the PwD/ restrictions** **Concerns of the PWD: Sense of being independent and Autonomy of the PwD**	**Interviewer: How do you feel the responsibility of caregiving being the only member of family?** **Main Caregiver:** I think it as my duty... My parents gave birth to me… I arrived in this world thanks to them, got a body to live in this world... Therefore, I'll do it as a duty... untill I live... and as I could... no bond... I'm not glued on her... Just as a duty... [Reflection: she is so religious, all her thoughts throughout our discussion based on Buddhist concepts... And the way she perceives her caregiving 'as a duty being the daughter, no such attachment towards mother – duty/ as a reciprocation] **Interviewer: How do you manage time for your personal work with the activities of caregiving? How much time you spend for your self?** **Main Caregiver:** Personal work…? You know, that doesn't happen as the way I want them to happen... Perhaps I have only hour so two per day... that's also during the night… It's only during the night I have time for my work. **Interviewer: What does that mean? Do you feel like you haven't got time for your self?** **Main Caregiver:** Yes... Yes… I am now mostly devoted for this... [caregiving] Or else.. today [some friends] went on a trip [pilgrim]. I was invited too. If I joined them, I don't have to spend a penny, I could just go... But, I couldn't leave her. I have no way of leaving her alone even for few minutes... Just like looking after a three year old kid. [However, earlier she said she goes to market leaving her mother alone at home.]	Normal life style of the family members: -Daily Buddhist rituals Lack of sleep, need to be vigilant and control her activities due to safely reasons Day to day struggles of the main caregiver because of the forgetfulness of her mother -Repetitive talking, and behaviour -difficulty in organise work with interference of the PwD Need to feel useful to family Need for dignity and independence Need to be independent

Allowing PwD's freedom Vs Safety needs **Risk of falls/ injury** **Safety concerns: Vigilance** **Connectedness:** **-Support from others/ friends/neighbours** **-commitment to care**	**PWD:** Child.. Are the curries ready now? Time will pass... [**We were at the kitchen, we talked while she was cooking… The PwD came to kitchen and asked whether Samanmali finished cooking]** **Main Caregiver:** It's time for 'Buddha pooja' [offering]. That's what she trying to tell... [Reflection: Some of the Buddhists offer first portion of their meal to Lord Buddha before they eat, as a ritual] **Interviewer: Aa… Is she keen to do those rituals?** **Main Caregiver:** Oh no... She has no idea about the time... I usually offer *Buddha pooja* [offering meal to Lord Buddha] around 11 o' clock. She starts yelling since 8 or 9 in the morning. Now, yesterday I hid the box of matches... I needed that to lit the fire at auspicious time. [Refletion: It was a new year ritual. People lit the fire at an auspicious time on the new year day. I conducted the interview the day after of New year. She was worried her mother would do that before the time, as she has no idea of the day and time] She wants to do the chores... But I don't want her to work now. I ask her not to, because it doubles my workload [sense of burden] But, she doesn't like to live by herself... I think... that's her nature, because they used to work for long time… [Reflection: This PwD was a very hard working woman when she's capable of doing things... She has worked in a rubber state as a rubber tapper, also was baby-sitting for neighbourhood kids. Perhaps that make her feel useless when she has to live without doing any productive work. I remember in my very first interview also th PwD had similar concerns. He was	Normalising behaviour – as her habit **PWD likes to work, doesnot accept her physical inability to work** **-PwD's emotional need to be useful** **Caregiver is worried about the danger of falls** **Preference for Alternative treatments** **-Use of ayurvedic remedies instead of western medicine (not for dementia though)**

	wandering and when I asked... why he ran away, he said 'I was looking for a job. Those days I had enough money. I earned so well those days.. Now, I can't just eat from what my son-in-law earns. Can I? Comparatively… This older lady was the one who cooked and lead the house for a long time.. Perhaps she misses her duty to family and wants to feel productive]	**Caregiver's preference: Use of ayurvedic remedies instead of western medicine**
Need for over concern on safety	Now, other elders would say 'No, I can't handle this trouble' but my mother is not like that. She needs to work all the time.. [pause] Ahhh… and the risk of falling is high... now she fell down three times...	**Acceptance -They are old**
	Interviewer: Why? what happened?	**Lack of control/ Stuborn**
Safety concerns and challenges of care	**Main Caregiver:** Once, She slipped and fell down near the tap... Another time, it was three thirty in the morning... right here… near the front door... I was in the toilet... She had tried going outside... She fell down there... [showing the door step] She is lucky; didn't get any injuries... That is why I grew grass here...	**There is a risk of leaving the PwD alone at home**
	Main Caregiver: Yes. She fell down at the door step. Had a bruise on her face... I had to prepare her medication for nearly one to two months. [Ayurvedic treatment] it was not easy looking for herbs and preparing them. It's good I had support from others [friends and neighbours]. Otherwise it's not easy for me to do this. Everyone is helping me. Once, amma fell down again and I had to admit her in the hospital. A friend of mine came and offered to stay with her... That was a big relief… But, I couldn't let her stay there... I was the one who knew amma's condition well... So I stayed with her that night. [Reflection: It sounded like falls are additional burden of care. She thought mother was being stubborn as her mother	
Meaning: Caregiving as a learning experience		**Suggest poor awareness about dementia symptoms. She compares**

Illness perception **PwD destroyed her blood reports**	did not listen to her. According to her, friends, relatives and neighbours are there to help whenever she asks. And it's a relief. But, it seems she doesn't like to be a burden to others and she tries her best to manage things her own with out troubling her friends - Sense of Responsibility/ Commitment? May be her ego/ pride prevents seeking support. She said she is afraid of falls, as it doubles the caregiving responsibility, so take precausions to prevent falling. Rather than western medicine she trusts Ayurwedic medicine, even though it is hard to find ingredience and recipie for the therapy.] **Interviewer: Ah... So you stayed with your mother?** **Main Caregiver:** Yes. But, I didn't have to stay long. She vomited once, so they wanted to keep her overnight at OPD for close observation. They took three x-rays. And she was discharged next day morning. Later, I did Sinhala herbal medical treatments for her... Thing is... they are old now, so [bones] are very week.. It will be very difficult if damage occurs. That's why I have take precautions to prevent her falling.. I made a fence here so she can walk to toilet with help. But she is so stuborn; she goes out and visit [neighbours] when I went to market. **Interviewer: Does she forget the way back home when she goes out like that?** **Main Caregiver: N**o no... She can come back with out any problem. Now, when I go somewhere she usually locks the front door, and opens it when I come back... She can do such things... Sometimes she locks the door inside [an additional lock] and then I can't open it from out side.	**her mother with other elders known to them** her general opinion about illnesses/ illness perception **-Illness is due to imbalences of spiritual power of the universe** **She prefers her own remedies for any illness, She doesnot like western medicine at all.** **This attitude of the the main caregiver affected with PwD's treatments as well. PwD was not on any medication, was not attending the dementia clinic by the time I interview her.**

Trust on Gods/ Religious beliefs **upport** **Illness perception -cause by evil spirits** **Traditional Healing practices** **-mantra** **-pirith chanting** **-drinking holi water** **-wear chanted threads**	[Then it was time for her to offer meal to Lord Buddha and worship, we stopped recording the conversation for about 30 minutes for that. She started preparing the offerrings. Meanwhile she explained me her daily rituals, about the Dammha sermons she attended] **Main Caregiver:** Now, I'm used to this [caregiving] I'm ok with it as I have some experience **[being with her]** or else… [Reflection: She sounded like with experience she learned to tolerate mother's behaviour] Her age is 83 now, but she behaves like a kid aged 3 – 4 years... sometimes she is in 30s… Not everyone in our family behaves like her... Now, one of our grand father, my mother's uncle… still very mindful. He still comes alone to the town to collect his pension. **Interviewer: Aa…** **Main Caregiver:** Sometimes… Most of the current diseases we get as a result of our own faults. They are not natural. If you can live with the powers of the univers [spiritully] there are no issues. Even eating and drinking, You know… Now, I had flem in my chest... like I had Pneumonia. I got sick when I was in *'Dambadiwa'* [India]. I am not afraid to die, not a bit... Doctor asked me to admit for a day and get a check up at cancer hospital, he was suspecting whether I have a cancer. It's been two years now, I didn't go. It's like this, child [she called me child]… I understand my body and my illnesses… But I didn't want to discuss them with the doctor. So I kept quiet. I actually met the doctor as I wanted to get rid of the flem I had... but it got worse after his medication. I developed a dry cough after that... Finally I ate onions, did that and this... and got well. I kept the blood	**She held strong religious beliefs in general** **-God protected me during the pilgrimage** **Relatives helped her to take a break from caregiving** **Dead relatives caused illness?** **Her strong belief system on Buddha, and spiritual influences on illness and cure made her practice spiritual healing methods** **Some Buddhist monks play a role as traditional healers.** **-there is evidence in the history of Buddhism where**

Trust on Complementary healing rituals **Dependency** **Meaning : Attributing to the supernatural causes**	reports to show you... But amma has put them on fire… She can't leave any paper, she put them on fire. She even put all my **'Budusarana' [a religious magazine]** on fire. [most of the families in Sri Lanka still use the firewoods for cooking instead of gas. Her mother uses all the papers in her arm length to set fire when she starts cooking.] I went with a neighbour [a nurse]. Doctor asked me 'get admit right now!', but I said I can't. [She does not believe in western medicicne. This may be a reson for her being not interested in seeking medical advice for her mother's condition.] **Interviewer: Ahh!** **Main Caregiver:** I went to India [on a pilgrimage]... That's where I got sick... I couldn't eat... I think the issue was with water... My body was weak... but not my heart... It was with the Gods help I succeed my ambision to [see the places where Lord Buddha lived]. Oh... triple Gem blessed me..! I visited all the places... Even 'Gijja kuttah..' **Interviewer: How did you arrange the caregiving during those days?** **Main Caregiver:** My cousin sister was here with Amma... Otherwise, I can't leave her alone… Can I? Those days she was not this ill. Things had happened in my absence and by the time I return.. There were many issues here... You know… Issues of evil spirits... **Interviewer: Means? Can you explain a little?** **Main Caregiver:** Means... dead spirits... of my father... and aunt… and my grand father… Mother was affected buy their evil spirits... [They all have died some time back and she	**monks were trained to practice traditional medicine. Even spiritual healing using mantra and pirith chanting** **Buddhists believe that chanting of Pirith has a healing power, and gives protection from all the evil, illness. The power comes from universe with the meanings of the Pali terms used in them.** **Belief:** **-Pirith chanting can protect them from evil spirits** **-When you drink holy water it increases the apetite so mother could eat again** **She could eat with the treatment (drinking holy water)** **She believes the evil spirits can not cause any troubles as she is so religious?.**

Financial Support from Relatives **Support from neighbours and friends -financial** **Very good support system available for her. Not only for matters related to caregiving for the person with**	strongly believed her mother started behaving abnormally due to influence of these evil spirits] This place was a real mess when I return. **Interviewer: Is that a posession? Can you please tell me more about it?** **Main Caregiver:** Not only a posession... It was like… Amma was not eating anything... But, others were looking after her well... really... But they said, she couldn't eat or drink anything all of a sudden. With out any reason. **Interviewer: Hm.... Then.. What did you do?** **Main Caregiver:** Meh..! I met a monk... and told him the details...[who is famous for chasing away evil spirits]… I only offered him 500 [rupees] Then he revealed the story, and told me what to do... I myself did all the things... If someone else did it... It would cost me about two laks [rupees]... It was all about Pirith chanting.. That's why I trust that... [Theme – Trust].. Whatever I do... I do with the trust for triple gems... Until I obtain nibbhana... That's all I trust. My determination is to attain Nibbhana someday...Untill I reach there I have no help other than the triple gems. [Theme – Trust/ Strong religious faith and beliefs of the power of pirith chanting to chase away the evil spirits possessed by her mother] When the life insurance people come... I used to tell them... *'I don't need anyother insurance... I already have my triple gem insurance!'* That's for lifetime... and no need to pay a monthly instalment. [pause] [and she said she didn't buy the life insurance]	**(Buddha has taught 'one who lives according to Dhamma is protected by Dhamma it self)** **Traditional belief is that the evil spirits brings bad odours with them, they make noices to fear people, or hurt them by pushing, dragging, appearing in dreams or other ways.** **She is much relieved as she got emmence support from others in every possible way.** **She has no time for a job due to caregiving, but she has support from others – no much concern about financial matters** **She managed to stay religious and offer meal to temple while giving care to**

dementia. For other things as well. **Confidence to continue care** **Perception towards receiving support -Pay off merits of her good lifestyle and living according to Buddhist teachings** **Meaning of Caregiving: Responsibility** **Sense of burden**	Then, There were pirith like 'Rathana suthra' to chant 21 times… in ascending and descending order... There's one more... it was supposed to chant 1000 times, another 108 times... [the dasadisa piritha' Like wise... I told you she couldn't eat.. and the monk instructed to chant a 'gatha' 21 times with pirith.. Then only she could eat.. [Usually they chant pot of water with pirith and let the affected person drink that holy water.] **Interviewer: A.. ha..** **Main Caregiver:** She says she is safe when I'm around. Nothing happened when I'm here. It seems the eveil spirits can't come when I'm around... So, Amma doesn't like to be without me.. She says, When I'm not around they [spirits] are trying to take her... [Reflection: She sounded like she has a power to chase away the spirits as she is so religious. Perhaps the PwD doesn't want to be alone and she is very much looking for her daughter's affection. Since she's away for about a month during her pilgrimage to India she must have developed loss of appetite due to psychological reasons such as lonleness, anxiety and confusion state. But, they both believe this was due to some kind of supernatural influence of bad spirits of their dead relatives – Illness Perception.] Yes.. It was very late when Amma told that to me, you know... I did all those [remedies] after she told that to me... As I realised it all happened when I was away, during my pilgrimage. When I returned I sensed it… there were bad smells... later I did many things... Protections [charms] to amma and house. I have a cousin sister who works abroad... She asked to hire	**her mother fulltime, others help her financially for things not related to caregiving as well.** **Perception towards receiving support ffrom others** **She thinks she receives support as a result of being religious, or doing meritorious activities, - Faith in Karma** **Life philoshphy of the caregiver – simple, carefree life, giving and religious** **Connectedness- Maincaregiver is not emotionally attached to her mother. Caregiving is just a responsibility**

Transformation of self: **Acceptance of circumstances in life and live according to Lord Buddha's teaching/ a test for measuring her qualities?** **Meaning of Caregiving** **-a responsibility** **Sense of Burden**	someone [a devil dancer?] for these. She is the one who helped me a lot financially... She even shouted at me... for postponing things. She sent money for all remedies… And other friends also help me a lot. [Reflection: It appeared that she was well supported by the neighbours, friends and some of the relatives. Her support system is very good. And she is very much satisfied with that. They provide her psychological support, be with her, give her expenses and attend to her household requirements, even for her religious activities like alms giving] Now [a friend] bought me everything we needed for this new year... I think she bought me things worth more than 2000 rupees... from the packet of salt to rice... And clothes for both amma and me... I think that would cost more than a 1000 [rupees]. So everyone helps me. If I had to worry about those.. [silence] I don't have enough time for shopping... No time for a job... Earlier I used to sell mosquitonets that I sew. I used to sew them. Had a very good demand for them... Now I don't have time to do that… I am so grateful and relieved I have enough support in that way. I spend those money I earned for alms giving [dhana]… However, If something came to my mind... I somehow do it... Last time I gave an alms giving [to temple]... Nearly 65 monks were there… I think it would cost me about 40000 rupees... But, I had spent only about 3000 – 4000 from my own money... rest of the expenses were sorted by the donations received from others... Everyone supported me to do that... Next door neighbours gave rice from their	**Throughout the journey caregivers are fluctuating inbetween their feelings -love and wiliness to sense of burden.** **That seems situational.** **Learning to cope or adjust the feelings of anger** **Increased workload, PwD's irritable behaviour/ stubbornness leading to anger – Sense of Burden** **Reasons for getting angry at the PwD:** **-repititive behaviour** **-lack of control over PwD**

Perception of Caregiving: Caregiving is a learning process (anger management) **Conflicts between Caregiver and PwD as a result of control** **Illness Perception** **Challenges/ Sense of burden** **Meaning of Caregiving – it's a learning process**	paddy field... they always say, 'if you need any help, or want to go anywhere just give us a ring... or even a missed call... we will come and lookafter mother...' They are well off. But, I won't trouble them... not even relatives or friends... That's my nature... [she sounded very confident... her voice was steady and firm..] I am so determined not to trouble anyone for caring her... I will do these as I can... Otherwise… chuh…! That's my nature since early days... I don't like to trouble anyone... Perhaps It [help] comes to me automatically… because I'm religious. [she thinks because of her religiousness the best things will reach her and she has blessing of Lord Buddha and the triple Gems..] That my child, I think because I took refuge in Lord Buddha. Otherwise, it's not my luck, or my powers… There's no limit of those qualities of Lord Buddha.. I think all these support is a result of my religiousness. I always try to share what I have with others... I am contributing to alms givings.. do lots good work for merit... That returns to me as well. I don't look forward too much... I don't think too much about future… **Interviewer: Hm... Can you please tell me how the caregiving for your mother has affected your life?** **Main Caregiver:** Mm.. that… I don't think much... Just think it as my responsibility. [how she perceive the role of caregiving. Sense of duty.] **Interviewer: Is there any situation you feel it as a burden?**	**-vigilance and increased workload** **She justifies her responses/ reactions towards mother's behaviour** **Arguments and conflicts between the PwD and the caregiver as a result of way of communicating the message.** **Over control and Poor communication is leading to misunderstanding and conflicts/ arguments/ heartfeelings.** **Lack of awareness about the nature of dementia – forgetfulness as a deliberate act** **Caregiver faced different challenges.** **from the beginning** -fear and uncertainity -lack of knowledge what to do and how to do -fealings of helplessness

With time, and experience fear faded away and learned how to deal with the situation **Caregiver concerns:** **-PwD's health (nutrition, injury prevention and safety)** **-risk of falling/ safety**	**Main Caregiver:** Burden... Mm... At times I feel her as a burden; especially when I am unable to do my personal work beacause of her. But I think positively about it. Means, I see the good side of it. I do it willingly. In such situations I can test my self. At times I can realise whether there's patience within me... [Reflection: Her perception towards care giving, coping mechanism of the caregiver burden. Seems that the caregiving for years has changed the way she see things. Her life has been changed because of the caregiving, in a good way as she see it… 'she has learnt to be PwD'] **Interviewer: Hm... do you get emotional when you look after mother?** **Main Caregiver:** Like getting angry? **Interviewer: Yes. Emotions like that…** **Main Caregiver:** Why not... Most times I get angry... Try so hard to control it.. I think it's normal.. and I try to be patience.. **Interviewer: Can you tell me more about it. Like at wt times you get angry?** **Main Caregiver:** like.. When I have too much work... When I'm overwhelmed with work, and when she does exactly what I ask her not to... I get angry... If I ask her not to do something that's because she can't do it... She tries to cook, boil lentils, or set fire on heath... She can't see well now... What if she got burned… Even if I say no she is so stubborn... I get angry in such times.. **Interviewer: Hm...**	-being the one and only member of the family/ sharing responsibility **She has no proper plan for the future of her mother, care arrangements, treatment./do not over think** **Vigilance** **She still thinks the behaviour is deliberate/ not an illness** **Challenges of Care-Lack of control over PwD's behaviour** **Still the PwD can do most of her activities of daily living her self.**

Sense of Autonomy and independence of the PwD **Caregiver respects her autonomy and concern about being active**	**Main Caregiver:** She doesn't listen to me so often... Sometimes, she is very stubborn. I get angry at such times. I try so hard to control my self… I automatically get angry… I don't want to lie... [Reflections: This contradicts her religious understanding. Buddha's teaching of careing people are based on the four qualities 'meththa', 'karuna', 'muditha' and 'upekkha' (love and compassion, kindness, empathy, and acceptance of indifference)] **Interviewer: How do you feel about that later?** **Main Caregiver:** Eventhough I shouted at her, I don't mean it inside me... I do it for her own good… Safety first, you know. For example, I know she would get burned while set fire on heath... So I'm being tough... Then, she thinks I scold at her… I'm not actually scolding… Or else she doesn't listen to me... [She refers to her anger, shouting and control as a safety concern]	**She seems attuned to PwD's behaviour and knows how to help her without getting in to conflics**
Challenges of Care: **Lack of understanding of firstaid or how to deal in an emergency/ fall**	**Interviewer: Hmm... Usually how she behaves during such times?** **Main Caregiver:** Yes... She sometimes says... 'I don't need children like you…' Because I don't allow her to do certain things... I get more work because of her... At times she promise 'I won't do it again...', but then she forgets her promises next day... **Interviewer: Can you please tell me about the challenges you face when caregiving to your mother?** **Main Caregiver:** At first I felt like I won't be able to do this alone.. I really felt so. How am I going to face this alone? If I have got any brother or sister, I could have shared the responsibility you know... It was at the beginning... But when I get used to this... those	**Fear of being bed ridden, having a major injury like fracture as a result of frequent falls** **She doen't know about the importance of immobilisation if she suspects a fracture.** **Neglects self** **Neglegence of self care, health, rest and sleep**

Acceptance: **-the role as main caregiver** **Meaning of Caregiving:** **Caregiving is a learning process** **Awakening** **-Transformation of self by caregiving experience and religion** **Illness Perception-causation of symptoms by evil spirits**	feelings eventually faded away and I felt like I'm strong enough to face anything. [Reflection: From her words I could see her courage to face the situation alone, the strength developed with time defeating her fear of uncertainity and loneliness. Adjustment to the situation over time – positively – empowered with experience] With experience I automatically started thinking like that [I can manage things]… At the beginning I thought how I am going to face in an emergency situation... Now for example if she fell down... But, when that actually happened I somehow faced the situation... Now there's nothing new to think. Now I act according to the situation. I don't plan for future. [Reflection: Seems she is strengthened her feelings with experience, fear of uncertainity, fear of caregiving relieved with time... Perhaps she thinks over planning increase the stress level, so she has now decided to go with the flow... and act according the situation… She also taled about some safety precautions she took to prevent falls, keep good health] **Interviewer: Hm.. Have you ever thought of a better way to lookafter mother** **Main Caregiver:** No no.. I haven't.. Just do accordingly… attend to daily concerns. **Interviewer: Do you have any concerns about caregiving for mother?** **Main Caregiver:** Yes, her health... I am very thoughtful to take safety precautions to avoid every possible injury. Now I made a fence... to prevent her from falls... I usually pluck flowers for her before I go out so she doesn't have to do it... But that effort is useless... as soon as I step out she starts plucking them... Just few seconds enough to happen this [an injury], you know...	**Acceptance of caregiving role** **Perception that the Tripple gems blessed her to be empowered?** **Understanding of inevitability, coping with the religious beliefs** **She identifies the gradual deterioration of the PwD but do not relate that to an illness.** **Practiced traditional Healing methods instead of Medication – Medical pluralism?**

Illness perception: normalising the symptoms **Impermanance – change is inevitable/ nature of life**	[Fear of falls- this is another challenge she and many other participants complained about. PwDs behaviour, physical weakness, poor vision may increase the risk of falling. The caregiver is afraid of PwD being bedridden, or get injured as it doubles her workload, increase the caregiver burden and bring much stress to the caregiver. Some situations her concerns are on increased cost of caregiving and the difficulty to find herbs and ingredients she need for the traditional treatments.] **Interviewer: Can she manage her day today activities alone? Like bathing? Going to toilet** **Main Caregiver:** Oh yes she can... But sometimes she can't get herself cleaned while bathing, so I help her. But she doesn't like it. She wants to do it by her self. So I let her do that, sometimes I pretend like I only apply soap on her back. It's good for her to be active.. like dressing... or combing hair… Or else she would become more inactive… I want her to be active, so I let her do her own things. If not her hands and fingers will get weaker you know... I only assist her when she is ill or weak to do things by her own... Then I'm there for her, otherwise I let her do her own work... [Reflection: This is a very good example where PwD shows her **autonomy, and need to be independence**… She might get irritated and annoyed when her daughter try to assist her... From the caregiver's side her mom keeps refusing her support was a challenge... It was a pleasure to hear that she is giving some freedom to her mother atleast to do few work by her own... that matters for **psychological wellbeing** of the PwD... PwD get angry when they were controlled and always asked to do things they don't like, and when they were asked	**PwD has no other known illnesses or physical conditions** **Perceive forgetfulness as a normal part of ageing** **She also thinks it can not be normal when compared to other healthy older adults (So perhaps she is confused?)** **Buddhist phylosophy**

	not to do things they like... Perhaps that's why they behave agitated, and violent... I think they too need some sort of **autonomy, independence and decision making power** in small things that matter to them...] **Interviewer: Ah. Ok.** **Main Caregiver:** Now when she fell down I can't figure out whether there's any internal damage. I'm afraid to lift her up even if I can't find any visible damage. I asked her to try and get up. And I was there to hold her. Last time she fell down I did that. Usually I can lift her up and hold her alone. She walked well... so I knew there's nothing to worry. **Interviewer: Now… Are you concern of your health, like you think of your mother's..?** **Main Caregiver:** I don't think about it at all... [laugh] just go with the flow... If I started thinking I won't be able to do any other work. I don't regret about the work I cound't complete... Earlier I used to think that way. Now.. just go with the flow. [She seems **evolved through her own experience**. may be it's her coping mechanism… she might feel less stress when not thinking of unseen future... Sometimes... over thinking and over concern on things may cause much pain...] **Interviewer: Is there any particular reason for you to change the way you think now?** **Main Caregiver:** Reason I think, it's my experience as a caregiver... Otherthing, the religion I accept. According to Buddhist philosophy... I managed to make my mind to some extent... Not much I mean… a little improvement. It's the blessing of the Tripple Gems which made me so strong and gave this strength to face anything in my life. That's what I believe.	**Misinterpretation of the forgetfulness** **So, she thinks forgetfulness/ ability of being mindfull is a result of Karma?**

	[Reflection: her fears and pain now neutralised over time with the fact that caregiving has become a habit… She thinks the reason might be her **experience of taking** care of things alone.. and her religious belief... being a strong Buddhist and follower of Lord Buddha... she has prepared her mind to face the reality. – **Religious Influence]** **Interviewer: How do you think of the progression of mother's illness? Do you see any improvement with time? Or not?** **Main Caregiver:** She is getting weak. day by day. No concerns of her grooming. Early days she was not like that. She likes to stay clean and fresh... Lately she became bit untidy and unclean, was even reluctant to wash her face you know. I had to force her... I think the influence from evil spirits also might affect her... However, I did the needful for that... Even without medicine or treatment she got better after those rituals. Those days she was so untidy, very reluctant to bath... **Interviewer: Have you ever sought medical treatments for this condition?** **Main Caregiver:** No... I haven't. Not for memory loss. We don't take any treatment for that. But, sometime back she got phneumonia and we took western medicine. She also has hemorroids, we do Ayurveda treatments for that. And when she fell down she got bruises all over the face, that was also treated with Ayurvedic medicine. She is not on any other treatments from the hosptital... No pressure or cholesterol… nothing...	

	Now… Last time we checked them when she was taken to hospital after she fell down. Nothing was detected by then. Usually we don't check regularly. No any other illness to my knowledge. She doesn't prefer sweets that much. Just 'Mari' biscuits. **Interviewer: Mm.. How do you see her forgetfulness? I mean do you think it as an illness? Or is it a normal thing? Can you please tell me your idea?** **Main Caregiver:** Well... I don't know... I haven't a clear understanding. I think it's normal when I compare others at her age. But, I have also met elders in their nintees but in good mental condition. Therefore, I can not exactly say that forgetfulness is normal with aging. Because there are people with good memory and health... [Reflection: Seems she has no clear idea of illness perception] **Interviewer: Hmm... based on your religious views what do you think?** [She has a strong view on Buddhism and she and her mother has conflicts of her belief and the dementia condition.] **Main Caregiver:** According to Lord Budda, everything is impermanence... He preached about change... birth... getting old… death... these are common to every one... That's how I feel. When you match the reality of life with Buddhist philosophy it's very true… Now mother is 83… And she can't do the things she did at her age of 20... That means she has changed... Impermanence… But amma thinks she is still thirty... She doesn't like to accept it either... **Interviewer: Is there any other possible reason which lead her to this condition? Perhaps any thing happened when she is young?**	

	Main Caregiver: That of course I don't know… I have no idea what happened in her life when she's young. But onething... she is so fond of being with children. even before she got married she had been baby sitting other's kids. But, when I was a kid. I spent most of my childhood with my grandma. I think. she [grand ma] is one of the reasons for my extreame religiousness. Perhaps I had a habit from previous lives too. However, she was so religious... she was far ahead than any of us... She lived 94 years. But, I have never heard she complain about any illness... or physical pain. She had a chest pain on the day she died. She is very clean, and tidy... had a nice scent came from her soap... when compared to that my mother is so different. Like I said before, we can't compare or say all are same… **Interviewer: What is the reason for that, as you think?** **Main Caregiver:** I always come to the same point... If I take it religiously… mind comes from previous lives, you know… It's the 'Karma'... The repucussions of Karma is the result of your actions. Now if I get angry at her it's not my mother's fault. I see it as my fault. Otherwise, If I could make my mind and leaned to be patient in such occasions. I won't get angry at her... Now a days, I am not that angry for her actions.. At the beginning.. to be honest I was very much angry at her.. when time passed, I realised.. all these things are useless.. [She has realised impermanence of life] when compared to those days.. I'm not angry at her now.. I've learned to stay calm.. I can be patient 90% of the times.. **Interviewer: Hm.. you told me before.. that there are many people to support you. Are you satisfied about this support?**	

	Main Caregiver: I have no expectations as such to receive support from anyone.. If I get support, it's alright.. Even if didn't that also fine.. I'm neither happy.. nor worried about it. If some one gave me any thing, I accept it and pass merits to them.. [say '*pin*'..]It could be useful to me.. perhaps not.. But I don't want to upset anyone saying no.. for example.. food. Mostly I get things that we really are not prefer to eat.. But I accept them.. and give away to someone who need it more than me.. So, I'm neither happy nor worried when I get things. **Interviewer: hmm..** **[I spent some time with the PwD.. She was showing some photos of her with her favourit monk during a religious festival]** **Main Caregiver:** She is so concerned when someone visits her. She adores them than me... It's the nature of most older people.. Not only our mother.. That happened toa friend of mine too [laush]. She was the one who did everything for her mother.. She also had a brother.. When her son visits to see her once in a blue moon.. my friend's mother feels so high.. **Interviewer: Can you tell me what type of support you expect from current health care system when caring for your mother?** **Main Caregiver:** I can not exactly name them.. We take medicine only when something happens, you know... unless I act according to that situation.. Now, this walking stick... is a wooden one.. I was thinking to get a walker... so she can walk with out falling... But... She doesn't even use that walking stick, just walks by herself... She doesn't use it unless I remind her to take it… Now I think getting a walker also a useless thing..	

	PWD: She wasn't at home.. I fall down here… When I'm coming back to house... Misee [nurse - next door neighbour is a nurse] heard the sound and came running... **Main Caregiver:** That's about her fall the other day.. **Interviewer: Hmm.. I think, I got to know so much of information.. Could I ask one more question? Have you ever heard a condition called 'dementia'? Or an illness that cause forgetfulness?** **Main Caregiver:** No.. No.. I haven't heard of that name.. mm…. Forgetfulness.. [pause] Is that an illness.. But this name.. No.. **Interviewer: Thank you very much!**	

Summary of the Analysis

- Strong beliefs (religious beliefs and traditional treatment methods) directly influence the treatment methods, nature of care giving.
- Caregivers struggle with concerns of safety, vigilance and controlling the behaviour of the PwD.
- Negative way of communication (scolding, shouting) leads to misunderstandings and conflicts in between the caregiver and the PwD.
- Meaning of caregiving evolve/ alter/ change with time and the experience and also the situation
- Preferred care model – Religious and super-natural